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CHILDREN AND YOUNG PEOPLE WITH DISABILITIES (INCORPORATING CHALLENGING BEHAVIOUR)

FAMILY RESILIENCE WHERE FAMILIES HAVE A CHILD (0 - 8 YEARS) WITH DISABILITY: FINAL REPORT

Report Prepared for the Disability Policy and Research Working Group

SPRC Report 10/08

Social Policy Research Centre, UNSW
Disability Studies and Research Institute
June 2008

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1 Executive Summary

In September 2006 the Disability Policy and Research Working Group[1] engaged the Social Policy Research Centre (SPRC) at the University of New South Wales (UNSW) to complete a research project entitled 'Children and Young People with Disabilities (Incorporating Challenging Behaviour)'. The research aims to increase the understanding of family resilience in families where a child (0 - 8 years) has a disability and to inform service provision.

A qualitative methodology was used to research family resilience in families who have a child aged 0 - 8 years with disability. The research was conducted in two parts – a literature review and primary data collection with families (where a child 0 - 8 years of age has a disability) and other key stakeholders, such as service providers, family advocacy groups and government officials. Eleven families where children under eight years of age have a disability were interviewed in March and April 2007. Thirteen key stakeholders from advocacy groups, government service providers, non-government and private organisations and government officials at the policy level were also interviewed.

This report summarises the findings of the final report, which focuses on the findings from the primary data collection with families and stakeholders. It develops the understanding of family resilience in families with young children (0 - 8 years of age) with disability. This component of the research also analyses service practices and models in order to identify and define elements of practice that build family resilience, detract from family resiliency, and are crucial to the maintenance of resiliency. It concludes with a section on how services can assist families to build and maintain resilience. This report should be read in conjunction with the literature review.[2]

1.1 Understanding family resilience

Family resilience is not a trait, static entity or an absolute. It is a process that will change over time and exists on a continuum of levels. Family resilience where the family includes a child with disability can be described as a process that includes three steps:

- crisis/adversity;
- drawing on strengths and resources to adjust; and
- adapting and resuming family functioning adversity, resources/strengths and adaptability.

[1] The Disability Policy and Research Working Group is a working party to the Community and Disability Services Ministers' Advisory Council which discusses Commonwealth State Territory Disability Agreement management issues and oversees the development and implementation of the Commonwealth State Territory Disability Agreement work plan (http://www.facsia.gov.au/internet/facsinternet.nsf/disabilities/policy-cstda.htm).

[2] See www.sprc.unsw.edu.au.

When confronted by adversity, families draw on their strengths and resources – those internal to the family and individual family members and external resources such as services – so they may adapt to the situation. From this, the family is able to recover from the adversity; they are able to regain a pattern of family functioning, despite having to make some changes. Importantly, this outcome is one that families are able to achieve and maintain over the long term despite shifts and fluctuations in family resilience over the short term.[3]

Stakeholder perceptions of family resilience

From the interviews, we found that stakeholders consider 'family resilience' to mean:

- intra-individual and intra-family qualities that get them through times of significant crisis and day-to-day challenges of disability and family life;
- the ability to 'bounce back';
- equity of access to opportunities;
- freedom of choice; and
- adequate external supports.

Overall, the responses of stakeholders reflected the intrinsic relationship between intra-individual and intra-familial strength and the supports they receive – from their own communities and from the disability and broader service sector.

Family case studies: facing adversities and stress

The families interviewed were all going through the process of resilience to varying extents. They experienced numerous occasions of adversity, crisis or very stressful experiences; they were constantly reacting to these situations and having to renegotiate routines and restabilise family functioning. All of the families spoke of experiencing crisis and adversities associated with particular events, including:

- birth;
- diagnosis and assessments;
- accessing services for their child with disability;
- hospitalisations (emergency and planned);
- therapies and treatments;
- financial pressures; and
- the compounded effect of having other family members with high level needs.

[3] For further discussion about family resilience see Muir, K. (2006). *Family resilience where families have a child with disability: literature review*, Report prepared for the Disability Policy and Research Working Group, Sydney, Social Policy Research Centre, University of New South Wales.

Parents, mothers especially, also reported being under stress from a lack of sleep due to the extra demands of caring for their child with disability.

Family functioning

Family functioning plays an integral role in family resilience. Most of the interviewees reported that the family's functioning often revolved around the child with the disability; they were frequently negotiating the resilience process by changing or adapting their family functioning around the needs of the child with the disability.

Work and education

Work and education commitments ensured some levels of family functioning remained fairly stable, at least for the family members involved in these activities. In all of the couple families (except one, where the responsibility was shared), the fathers were the primary income earners.

Generally the fathers' working week routines remained relatively stable compared to their partners. However, having a child with disability impacted on some fathers' decisions regarding their employment. Fathers' work demands also increased the burden of caring responsibilities on mothers, in particular increasing the difficulties of caring for their child with disability.

Only a few of the women interviewed were working. One was able to work full-time because of the flexibility of her and her husbands' employers. The other two women working did so part-time. Mothers' work was important in:

- balancing out mothers' needs;
- providing some stability and routine to the week; and
- providing additional income to enable their children with disability to partake in activities other children are likely to have the opportunity to participate in.

Caring responsibilities

Unsurprisingly, caring responsibilities dominated most routines and how the families functioned day-to-day. Routines for the mothers with young children largely revolved around early intervention and therapy appointments. While there are often specified days for appointments, the list of therapies coupled with essential, unplanned medical appointments, illnesses or behaviour problems, mean it is difficult for families to maintain steady routines. Caring responsibilities and medical problems also interrupted work and education commitments, particularly for mothers. Thus, these families experience a constant renegotiation of family functioning.

Many of the mothers interviewed highlighted the extensive time demands placed on them. When children are young, it is difficult for family functioning to not revolve around the child's disability. Once children are school aged, maintaining some routine becomes somewhat easier for some families because some routines are determined by school times.

Protective factors: resources and strengths[4]

The resources and strengths families have to draw on are essential in assisting them to maintain resilience: to overcome adversity, to adapt family functioning and re-establish normal routines.

Good communication and problem solving

All family members interviewed, except one, identified good communication as a strategy for solving problems within the family. These discussions occurred between partners and partners and children. Also, the families' belief that they have the capacity to solve problems was often determined by whether they felt the problems were within or outside their control.

Balancing family relationships

Balancing the needs of all family members (not only the child with disability) was a challenge for most of the families interviewed. The hierarchy of meeting family members' needs was generally addressed in the following order: the child with disability, siblings, individual parents (often the father first) and couples.

In all situations the mothers were the primary carers for the children. In a few situations, there was a clear delineation of roles. Therefore when extra caring demands were placed on them, women in these situations often absorbed the extra responsibilities, leaving them little time for themselves.

In other family situations, fathers took on more responsibility to provide their partners with time away from the children. However, spending time together as a couple was often compromised. It was recognised that many new families experience this, but it could be more pressing for families where a child has a disability because of the additional demands required in baby-sitting. Family holidays were identified as being really important for families to 're-connect'. This was not an option for sole parents, who expressed particular difficulties in finding time for themselves and financial resources for holidays.

Addressing the needs of siblings was prioritised, but parents also found this to be a challenge because of the time required to care for their child with disability. All of the mothers reported that their other children 'miss out' in terms of receiving sufficient attention and having their needs met. This had implications for siblings' behaviour, their capacity to be involved with their friends and participate in the community, particularly for those in rural areas.

[4] Spirituality and 'finding meaning' were two other issues identified. However, these were issues for few families and were not described in great depth. Thus, they comprise short sections of the full report and are not discussed in this short report.

Parents attempted to spend time with their other children when these children 'don't have to compete' with their brother or sister with the disability. Some parents were battling to balance instructions from therapists with the needs of their other children. The other issue raised by three families in regard to siblings was their role as young carers. The supportive caring roles siblings play are an important resource for parents, yet parents are also mindful of the responsibility and time constraints this can place on their children. Balancing other children's educational needs, social needs and family responsibilities was a concern for the parents interviewed.

Hardiness

Another protective factor is having a family that works together in difficult times. All families identified some emotional strengths and tangible strategies that they believed make their families durable. Traits such as being 'cohesive, self-sufficient, optimistic' and 'in it together' were mentioned. Couples reported having strong relationships that are 'lovable, close and affectionate'. Parents also drew on the strengths of other family members. Not all families believed they were durable and, in some cases, partners did not always agree about the family's hardiness. Two mothers reported that their families are sometimes able to endure difficulties and other times not.

Social support

Maintaining relationships with relatives, friends and others to keep up social interaction, avoid social isolation and ensure a network of people who can provide practical and emotional support when required can also protect families.

Informal support from extended family members and/or friends is a common source of support for most of the parents interviewed. This support ranges from emotional to practical support, such as financial assistance and child care.

All of the couples cited each other as their main emotional support. They generally reported friends or extended family as the second most common supports and thirdly support groups, such as on-line or community based disability specific groups. The sole parents interviewed relied on friends, extended family and services for their emotional support. Two sole parents, however, appeared to be dislocated from their local communities because they were not emotionally or socially linked with other members of their community.

The women in couple families (with the exception of one) were able to readily identify at least one source of emotional support besides their partner. However the fathers involved in the interview process reported not having anyone other than their partners to talk to about issues raised by having a child with disability.

Even those families who had informal support available could not rely on that support when they most need it. This is an important issue for resilience and service provision; families with informal contacts still need extra support. Most respondents reported not being able to rely on extended family members**.** Fear, a lack of behaviour management skills, geographic separation, poor health and a preoccupation with their own

responsibilities were some of the reasons the interviewees gave for their extended families' lack of support. Even where practical support was available from one side of the family, there was some anxiety around the permanence of this support, due to their parents' ageing or geographical distance.

Friends were less likely to be primary supports for most of the interviewees. Some interviewees were reluctant to ask friends to help with child care for their child with disability because of the extra demands of care, their own family responsibilities and lack of awareness of how to treat and care for the child with disability. On the other hand, friends were helpful emotional supports and babysitters for the other children in the family.

Routines and family times

All families interviewed had periods of time they spent together, such as over meals, at church, going on picnics or holidays and doing other family based activities. While spending time together was found to be beneficial for families, it could also present challenges, conflict and/or stress if activities were affected by the child's disability. Behaviour problems limited the capacity of some families to interact socially or attend certain community events. Parents restrict the places families attend for social events to ensure there is no danger to their child.

Couples were more able to balance weekend activities for the range of their children's needs because they could share and/or divide responsibilities. Where older siblings could take on some caring responsibilities, families had greater flexibility to participate in activities. Sole parents were more socially isolated because taking their children, including their child with disability, out on their own was difficult.

Hope and flexibility

Stakeholders noted that when children with disabilities are going through diagnosis, assessments and disability management plans, their wishes, dreams and aspirations for the future sometimes 'get lost'. Maintaining these and working towards achieving them were considered by some stakeholders to be a central component of family resilience. These aspirations translate to future-oriented concrete, practical concerns and are linked in some way to the child's development and progress.

Most of the families interviewed had goals or hopes related to their children, such as being able to access required services and supports and for them to get a sound education. Most families hoped for happiness, for their families to remain strong and for the needs of individual family members to be met. Some families just hoped for a break away from the routine of therapies. While practical support may assist families to set and achieve some goals, there was less hope around goals for financial security. Relying on government support and having to limit employment due to caring responsibilities and the lack of appropriate child care can place limitations on the long term financial goals of families.

Financial management

The comments from stakeholder and family interviewees suggest that financial management and adequacy of income are important factors for families who have a child with disability. The majority of the families interviewed could not always afford the goods and services they felt were essential for their child with disability to achieve a reasonable quality of life. Two families could 'rarely' afford these goods and services and five could only 'sometimes' afford them. The remaining families reported being able to afford goods and services most of the time or all of the time, but nonetheless expressed concerns that their situation may suddenly change. They also described careful decision-making concerning their finances.

Openness

Most parents interviewed actively spoke with their children about what their sibling with a disability 'can and can't do'. One parent found it difficult to help her children understand their siblings' disability, and two parents stated they do not communicate well as a family. Couples also reported talking 'openly' with each other about how their child is going and about parenting. As the mothers are the primary carers and largely going to doctors alone, they often informed their partners about their child's clinical outcomes.

Empowerment

The level of empowerment of the parents interviewed is difficult to judge. However, parents articulated their feelings of control, or lack of, when dealing with service providers. In dealing with difficult services, one couple used a 'good cop, bad cop' strategy, in an attempt to bring the situation under their control and successfully negotiate.

Health

If adequate support services cannot be accessed or are unavailable, a family member's poor physical and/or mental health has the potential to unseat most of the factors listed as critical in protecting and strengthening these families. All except one individual reported their health as good or very good at the time of the interview. However, one of the women who reported good health believed she 'may be suffering from depression'. A few of the parents interviewed exercised for stress relief, but not all could allocate the time for regular physical activity.

Issues that Threaten Resilience – Risks for Families

When asked about the risks they see their families possibly facing in the future, none of the families stated that they are concerned that their families will separate or relinquish their child.

The families' own concerns for their future include:

- issues associated with their child with disability getting older: schooling, increased weight and being able to carry them, about the time when their children were 'not as cute';
- future health problems and safety for their child with disability;
- who will care for their children when they are no longer alive;
- barriers associated with their geographic location and/or having to move to accommodate their child's needs or financial concerns;
- loss of financial security and/or increasing financial stress;
- difficulties accessing services in relation to supporting their child with disability; and
- the limitations imposed on their other children and the risk of their needs not being met.

Summary: Family protective and risk factors

- Having resources and strengths to draw on protects families and helps them recover and experience resilience;
- Families are most likely to use communication, emotional strengths and tangible strategies to deal with stress, solve problems and manage interfamily conflicts;
- Most families have difficulty balancing the individual needs of family members because of the time and financial resources required to support their child with disability;
- Couples spend little or no time alone together and sole parents have little or no time for themselves and appear dislocated from their local communities;
- Families are stressed about trying to address the needs of their children who do not have a disability;
- Sole parents and fathers are most likely to lack emotional support;
- Despite all except one family identifying sources of informal emotional or practical support, seven families reported not getting support when they most need it;
- Families sometimes socially isolate themselves because of barriers – financial, behavioural, transport, extensive caring – faced as a result of having a child with disability;
- Family interviewees hope for long-term goals, like positive outcomes for their children, and short-term ones, such as access to necessary services and supports;
- The majority of families cannot afford the goods and services they believe are essential for their child to achieve a reasonable quality of life;
- Most interviewees reported sound health; but the interviews reinforced the importance of emotional support for families; and

- Families worry about future access to services, their ability to cope with a child with disability as they get older, their financial security, geographic location and about their other children's outcomes.

1.2 Service Provision and Family Resilience

The purpose of this section is to integrate findings from stakeholder and family interviews to offer insight into the characteristics of an optimal service provision framework that can support family resilience.[5]

Formal Services and Supports used by Families

The families interviewed use a range of formal services and supports which can be categorised into community, disability specific, co-ordinated, medical, therapy, family focused and other government services. All families access a range of medical services, however, there was considerable discrepancy regarding access to other types of services.

Service Providers Facilitating and Hindering Family Resilience

The interviews with stakeholders and family members revealed key areas where services providers both facilitate and hinder family resilience.

Transitional periods

Transitional periods can be understood as shifts in circumstances. They reflect a point in time characterised by a change in need.

Transitional periods threatening family resilience were a common theme raised by stakeholders. They involve disability-specific transitions (such as diagnosis and assessment), and transitions that all children face, but that are compounded by disability. These include transitions into school, growth and development (such as puberty), care transitions between family and institutional care and transitions into employment and independent living. Transitions pose particular challenges for children, families and service provision. Their outcomes can have far-reaching and long-term effects on family resilience.

As many of the children are young, the birth and assessment periods were the major transition points that have significantly affected the families interviewed. These periods were very stressful for many of the interviewees. This is a critical time for families to receive appropriate support and therefore essential in supporting families in the resilience process. Therefore service providers play an instrumental role in either supporting families or compounding their stress.

[5] Section 5 addresses *how* services can assist families to build and maintain family resilience.

Accessing information and services

Learning about and getting access to appropriate services is an important step in families being able to adjust to having a child with disability (the first stage of the resilience process).

Most families felt ill-informed about services and supports available to them. Other carers or parents of children with disability were a primary source of information for many families. There was widespread frustration among the families that this information was not provided at the time of the assessment.

Eligibility for and availability of services and supports

Eligibility and assessments for services and supports repeatedly stressed many of the families interviewed, which negatively affects the resilience process. Delays with applications, appeals and rejections place families under considerable stress. They are frustrated by repeatedly having to demonstrate their child's level of disability and their need for services and supports.

Approval for services is further contentious when families are rejected or placed on long waiting lists because their child is not considered to be sufficiently "high need", yet the families believed they are critical for childhood development or family well-being. This was tied to dissatisfaction around the limited availability of services and the reactive nature of service provision, where support often only becomes available when families are in crisis. The availability of services in rural areas was a cause of stress for families and imposed significant financial and time constraints.

Service quality and treatment

The treatment service providers offer, with regards to how they relate to families and the quality of service children receive, is critical to effectively supporting families.

Families reported sound relationships with general medical services and were likely to report positive relationships with community supports, such as child care services. On the other hand, experiences with disability service providers were mixed. Families initially had high expectations of the supports they could receive from specific disability services and where these expectations were met families felt supported, but there was considerable disappointment and exasperation where this was not occurring.

In particular, families were likely to report good practice support as coming from individuals, rather than whole services. 'Exceptional' individuals were described as experienced, well trained, effective communicators, who provided consistent and regular follow-up and produced both positive outcomes for the child and the family. Thus family resilience was supported by some practices and threatened by others.

Service co-ordination

Where it was available and effective, service co-ordination could significantly support family resilience. Only three families experienced some level of service co-ordination.

However, this made a significant difference to their lives and the lives of their children. Other family members are keen for service co-ordination to be introduced. Co-ordination is important in rural areas to support families and to change the way services work. Stakeholders involved in programs with facilitators noted emotional support as being a key service provided by this model of service provision.

In only one situation did a family have an active case manager who facilitated the range of services the family received. This was perceived to be an incredibly valuable support and a very important factor in this family's high level of resilience. All families were adamant about the need for this type of support. They want co-ordinators who were well trained, well informed about the disability sector, and effective communicators who can inform them about the services they can access, offer some emotional support and help co-ordinate the range of supports and services they use.

Holistic support

One of the factors identified by stakeholders and family members that helps facilitate family strengths, and in turn resilience, is holistic support. Holistic support assists families to actively participate in their community and therefore acts as a protective factor in regard to resilience.

Interviewees referred to underlying cultures of practice that either embrace the child within the family and the community, or the child's disability. Resilience is not served solely by disability-specific interventions, but by strategies that recognise global needs. Respite care that was reliable and trustworthy was highly valued by the families interviewed. Families were looking for supports that were positive for their child with disability, and worthwhile for the family.

Community setting

The issue of community as a vital factor in family resilience was raised by many stakeholders. Coming from a cohesive community was noted as being characteristic of high resilience. Given the benefits of community cohesiveness, a number of stakeholders noted that enhancing this also enhances family resilience. For example, where respite care services are family based and children with disability are exposed to new and different experiences, parents feel supported. Community-mindedness was also raised by a service provider, whose respite service relies on volunteer assistance, as a resource that could be drawn upon to enhance family resilience.

Summary: Service provision – facilitating and hindering family resilience

- Transitional periods are critical periods where a family's resilience may be tested;
- Families reported experiencing most stress and negative experiences with services at the time of their child's birth and/or assessment;
- Learning about and getting access to appropriate services is an important step in families being able to adjust to having a child with disability;

- Many families experienced difficulty accessing information about appropriate and available services when their child was first born/diagnosed, but also ongoing;
- Families are strengthened by knowledge that their child is getting access to effective services, where some positive outcomes were visible;
- The eligibility process for services repeatedly frustrates families, especially where there are delays with applications, long waiting lists, the need to appeal, or rejections;
- Family resilience is hindered when families are under considerable stress because their child cannot get access to a service/support/therapy at a critical time in childhood development, not because they do not need it, but because other children's needs are deemed higher;
- How service providers relate to families and the quality of service a child receives is critical to effectively supporting families;
- Families are predominately content with the service relationships with mainstream health and community services, but are likely to be dissatisfied with some relationships within the disability sector;
- Families feel supported and are strengthened by service providers who are experienced, well trained, resourceful, communicate openly and effectively with the family, and who are willing to find and impart information and provide options;
- The one family that receives co-ordinated support from an effective case manager is one of the very few families who reported not requiring any additional support;
- Co-ordinated support is an important factor that facilitates family resilience;
- All families are adamant about the need for co-ordinated support; and

Family resilience is supported and strengthened by holistic supports that focus on the family unit.

1.3 How Services Can Assist Families to Build and Maintain Family Resilience

This section outlines practical support elements for consideration in service provision.

Strengthening families

A whole family approach is critical to strengthening families. Supporting family problem solving, mechanisms to maintain balanced family relationships and recognition of all family members are essential practice elements. Support for siblings is especially important because they often fall out of the sphere of focus. However, despite many policy statements about considering the 'whole' family, stakeholders reported that this often fails in practice. The concerns of family interviewees further reinforce the lack of holistic supports that work with siblings, parents and the family unit.

Listed below are a range of practice elements services could incorporate that may assist families to strengthen, develop or build protective factors.

Problem solving and communication

- Work with families to identify family strengths;
- Provide tools and resources to assist families to effectively communicate, solve problems and manage behaviour;
- Offer counselling to parents as part of an integrated service;
- *Systemic change:* service providers may require support to identify tools, train staff and work with families. A working group could consider funding the development of a specific 'resource kit' and training.

Balancing the needs of family members

- Reassure parents about the importance of participating in activities for themselves and provide the support (e.g. respite etc) for them to do so (this is especially important for sole parents);
- Offer holistic supports to assist families and couples to spend quality time together;
- Provide assistance with therapy within the home;
- Provide resources, supports and programs specifically for siblings;
- Increase availability of support for siblings who may be in young caring roles;
- Provide financial and caring support to assist families to meet the needs of all family members;
- *Systemic change:* funding models could include a specific statement that support will be provided to services to support activities that allows 'family time' of every configuration (family unit; parents as individuals; parents as couples; siblings; child with disability and siblings; child with disability as an individual).

Social support and family times

- Sole parents may require assistance to network within their communities;
- Network fathers in similar situations to provide them with some emotional support (systemic change: investigate the viability of an online source of support);
- Service provider and systemic change: eligibility for access to services should not necessarily be based on people's connection to family and friends because even if there are numerous connections they may not be providing tangible support;
- Provide integration assistant support for whole families to participate together in activities they may not otherwise have attended;
- *Systemic change:* community support groups, organisations and government services need to offer assistance with childcare (perhaps in the form of an integration assistant) to make it possible for children to attend activities and events with their parents.

Future hopes and risks

- Work with families to identify realistic goals and steps to achieve them;
- Forward plan with families for the short-term future, for example, 'what supports and services need to be accessed or what changes made to make the next twelve months easier?';
- Work with families to identify perceived future risks and strategies to deal with these risks;
- *Systemic change:* support families so they do not have to leave their rural networks/community to increase service access; or, if families are require to leave, actively support them to settle in new areas through networking and the provision of information;
- *Systemic change:* provide families with financial support – management, information regarding the list of financial supports they can access, practical support to purchase goods and services their child needs because of their disability, and ensure parents are able to work (if they want to) by adequately supporting their child;
- *Systemic change:* ensure families are receiving adequate support without older children having to leave school early to fill a substantial caring support role (especially in sole parent families);
- *Systemic change:* the broad intersections between disability, education and workforce participation need to be recognised as operating for families, as well as the child with disability. For example, a lack of support for a child with disability may mean reduced employment of parents and educational attainment of siblings. This relates to a systemic function that requires a long-term approach.

Strengthening services

Learning about disability: accessing information

- General disability information may be delivered via 'outreach' activities;
- Specific information concerning their child may be best delivered via a 'one-stop-shop' approach, where all relevant services can be accessed through one central point.

Timely access of services and transitions

- Increase the provision of information for families at birth and assessments about their child's disability and services and supports available;
- *Systemic change:* Base service frameworks on developmental timeframes specific to children: timely, rapid responses are of central concern;
- *Systemic change:* Train doctors/specialists at 'breaking the news' to families about their child's disability;
- *Systemic change:* A commitment from governments and service providers that the availability of services would be increased so that children with disabilities would not

be competing for limited places and families receive support before they go into crisis.

Effectively delivering support to families

- Where possible maintain consistency with individuals working with families;
- Train staff working for disability services/organisations on how to effectively communicate, negotiate and work with families;
- Provide families with negotiating skills to make them feel like they have options and an informed say in the decision making process;
- *Systemic change:* introduce/improve quality standards for therapists within disability services and working for government departments;
- *Systemic change:* structure the disability support system to assist services to provide life course support for families;
- *Systemic change:* support co-ordinators or facilitators to be mobile so that they can stay with families irrespective of changes in families' lives.

Service flexibility

- Offer flexible funding arrangements that may be directed toward the child and/or the family unit or other family members;
- Base service provision on priorities families identify; that is, families drive the service planning process;
- *Systemic change:* Introduce/increase flexible funding models that can be individually tailored to the family as a whole, the child, parents, other carers, such as grandparents, and/or siblings;
- *Systemic change:* focus further research on how funding models can achieve and sustain flexibility and responsiveness to families' changing needs.

Co-ordinated Support: The Facilitator Model

- A facilitator was given as a possible solution to many of the issues stakeholders and family members raised in this study;
- Families were especially eager for their access to services, supports and information to be co-ordinated.

Facilitator models were popular because they:

- Minimise the requirement for families to repeatedly demonstrate their eligibility;
- Assist families to navigate the complex and confusing disability landscape, both perceived and experienced;
- Allow parents to be parents, and not case managers or service coordinators;

- Provide families with information regarding their entitlements and offer emotional support.

The ideal facilitator model would have the following qualities:

- Committed to an early intervention approach;
- Well trained and well informed about the disability sector;
- Assigned at the time of diagnosis/assessment;
- Co-ordinates services to the child and family over the long-term;
- Improves co-ordination between services;
- Effective communicator who provides families with information, emotional support and helps facilitate trust with other service providers, such as volunteers or respite carers;
- Social work or psychology trained, as their perspective is broad.

Governance issues

From a governance perspective, it is important that future development of facilitator and other service provision models also consider:

- How disability interventions interact with other interventions and family circumstances and what the outcomes are for all family members;
- Inclusive practices into mainstream life;
- Achieving consistency of support across all domains of a child's life – home, school, community life, and 'fun stuff';
- How interventions operate across all domains;
- How policies and practices to 'do things smarter' with current resources;
- People from different demographic backgrounds, such as indigenous, sole parent and rural/remote families have particular needs that may require further address.

1.4 Conclusion

Family resilience is a process that includes three steps: crisis/adversity; drawing on strengths and resources to adjust; and adapting and resuming family functioning. The interviews (with eleven families and thirteen key stakeholders) reinforced that family resilience operates on a continuum that shifts and changes over time and is a process that families can repeatedly experience, often as a direct or indirect result of their child's disability.

The research found numerous protective and risk factors that families face in negotiating the resilience process. Having resources and strengths to draw on is critical for families to experience resilience. Most families have internal strategies they use to endure difficult periods or to solve problems; however accessing formal and informal supports also protects families. While the research found the majority of families receive informal

emotional and/or practical support, almost two-thirds of the families reported that they do not get support when they most need it.

Service provision can also facilitate and/or hinder family resilience depending on its availability, accessibility and quality. Numerous characteristics of service provision (especially receiving access to effective, high quality services at appropriate periods of time) were found to support family resilience. Some families were dissatisfied and feel unsupported by the disability sector. Disability providers, however, who are experienced, well trained, resourceful, willing to find and impart information, communicate openly and effectively with the family and provided options, help families in the resilience process. The co-ordination of supports and services that are holistic – that embrace the child within the family within the community – are also important factors in the resilience process.

There are numerous practice elements services can implement, develop or expand that work to improve services, strengthen families and help facilitate family resilience. For example, offering holistic support to assist whole families, and not just the child with disability and work with families to plan for the future – both helps achieve goals and combat risks. There is overwhelming support among families and stakeholders for the facilitator model. Families where a young child has a disability can be supported through the resilience process if service providers assist families to build protective factors, plan for the future and counter risks, and if effective resources are available through holistic, flexible, accessible and high quality service provision.

2 Introduction

In September 2006 the Disability Policy and Research Working Group[6] engaged the Social Policy Research Centre (SPRC), University of New South Wales, and the Disability Studies and Research Institute (DSaRI) to complete a research project entitled 'Children and Young People with Disabilities (Incorporating Challenging Behaviour)'. The research aimed to increase the understanding of family resilience in families where a child (0 - 8 years) has a disability and to inform service provision.

To this end, a qualitative methodology was designed for use in researching family resilience in families who have a child aged 0 - 8 years with disability. The research was conducted in two parts – a literature review and primary data collection with families (where a child 0 - 8 years of age has a disability) and other key stakeholders, such as service providers, family advocacy groups and government officials.

The project plan included four components. Firstly, the research set out to define and describe the term 'family resilience' as it relates to families who have a child aged 0-8 years with disability; secondly, to describe the evidence that underpins the identification and practice of family resilience in the 0 - 8 years age range; thirdly, to analyse service models in order to identify and define elements of practice that build family resilience, detract from family resiliency, and are crucial to the maintenance of resilience during times of transition; and finally, to identify and present tools that can be used to measure family resilience in families with a child with disability.

The literature review (Muir 2008) defined and described the term 'family resilience' as it relates to families who have a child aged 0 - 8 years with disability.[7] It contextualised resilience, tracing the shift from studies on childhood to family resilience. The second part of the literature review examined how this understanding of family resilience could be integrated with service provision and the affect service providers and professionals can have on families and the challenges of implementing family resilience research into practice. It provided a descriptive framework of practice elements that service providers and professionals can use to assist families to maintain, build and strengthen family resilience in families where a young child has a disability. The report did not compare an exhaustive list of services, but rather focused on the key to good practice – service co-ordination – and provided a few examples of existing services that have been evaluated. The third part of the literature review explored the practicalities of measuring family resilience where a family includes a child with disability (0 - 8 years). It looked at the

[6] The Disability Policy and Research Working Group is a working party to the Community and Disability Services Ministers' Advisory Council which discusses Commonwealth State Territory Disability Agreement management issues and oversees the development and implementation of the Commonwealth State Territory Disability Agreement work plan (FaHCSIA, 2007).

[7] Family resilience as it applies to families with a child with a disability is defined and described in Section 4. Other components of the literature review have also been incorporated into this final report to inform findings from the primary data collection. For further detail, however, this report should be read in conjunction with the literature review.

challenges, problems and limitations for practitioners when attempting to measure family resilience and the reliability of these tools. This included providing examples of researchers and service providers who have developed, used and evaluated family resilience measurement tools. Finally, this section offered ideas of how service provision can move forward in regard to working with families on resilience.

It is within this framework that the final report is structured. Using the findings from the primary data collection with families and stakeholders, this report develops the understanding of family resilience in families with young children (0 - 8 years of age) with disability. It also analyses service practices and models in order to identify and define elements of practice that build family resilience, detract from family resilience, and are crucial to the maintenance of resilience during times of transition. Finally, it concludes with a section on how services can assist families to build and maintain resilience.

3 Methodology

A qualitative methodology was used to develop an understanding of family resilience in families where a child aged 0 - 8 years has a disability. Interviews with families and key stakeholders were conducted to understand the resilience process and determine elements of practice that facilitate and detract from family resilience.

3.1 Family Interviews

Eleven families where children under eight years of age have a disability were interviewed in March and April 2007. Advertisements requesting families with a child (0 - 8 years) with disability were placed with disability organisations and online support groups. Key agencies were also asked to identify and approach potential participants. Families volunteered to participate in the interviews and, where permission was given, interviews were recorded to accurately reflect interviewees' experiences, perceptions and comments. The recruitment of families endeavoured to capture a range of families from different demographic backgrounds. Interviewees included mothers and fathers, sole parent and couple families, children with a range of disabilities, families with more than one child with disability, Indigenous families and families from a range of urban, regional and rural areas (see Table 3.1).

Table 3.1: Family interviewees by interview type and demographic detail

Characteristic		Number
Total families interviewed		11
Face to face interviewees		8
Phone interviewees		3
Children with disability under 8yrs included in data		12
Children with disability aged:	2 years or younger	4
	3-4 years of age	4
	5-7 years of age	4
Other children with disability in households over 8yrs		6
Family member(s) interviewed:	Mother only	7
	Father only	0
	Mother and father	3
	Foster mother	1
Aboriginal and Torres Strait Islander families		2
Sole parent families		3
Families primarily reliant on government benefits		3
Geographic area:	Urban	4
	Regional	3
	Rural	4

Families in urban and regional areas were interviewed at a time and place convenient to them. Two families in rural areas were interviewed by telephone due to remoteness. To maintain the privacy and confidentiality of the families interviewed, pseudonyms are used and specific geographic locations are not provided. Families were comfortable answering questions about services and describing their experiences. Some were challenged and/or confronted by the questions about family strengths and resilience.

Description of family participants

Gabby and Brad

Gabby is a sole parent with four children. The family live in an urban area. Her youngest child, Brad, who is 3 years of age, has been diagnosed with a cognitive impairment. Two of Brad's siblings also have speech, behaviour and learning difficulties. The family receive government benefits and while Gabby reported they are financially 'reasonably comfortable', she can 'rarely afford the goods and services' she feels are 'essential' for Brad to achieve a reasonable quality of life.

Naomi, Bill and Ingrid

Naomi, her husband Bill, and Ingrid (an only child) live in an urban area. Ingrid is 2 years of age; she is deaf, has cerebral palsy and some cognitive impairment. The family are 'just getting along' on one income; they can 'rarely afford' the goods and services Ingrid needs. Ingrid was born prematurely at 28 weeks, and was in the neo-natal unit for 3 months.

Kelly, Robert and Jasmine

Robert and Kelly live in rural NSW. They have three children. Jasmine, their youngest child, was diagnosed with Down Syndrome when she was one day old and also has dysphasia. She is now six years old, attends school and uses Makaton to communicate. The family are financially 'very comfortable' on one income and reported that they can 'always afford' the goods and services available in their community to support their daughter.

Carrie, Joshua and Hank

Carrie, Joshua and their three children live in remote NSW. Hank, their youngest child, is two years old and has cerebral palsy. The family 'just get along' on one income. They can 'sometimes afford' to buy the goods and services needed to support Hank. Hank uses a 'specially modified pre-wheelchair' within and outside his home. His mother described him as a happy child, who enjoys company and dislikes being alone. Carrie works hard to involve Hank in community activities.

Jacinta, Alex and Artie

Jacinta and Alex have one child, Artie, who is five-and-a-half months old and has Down Syndrome. They live in urban NSW. Both Jacinta and Alex work; they are financially very comfortable and reported that they can 'always afford' to purchase the goods and services Artie requires. Prior to Artie's birth, Jacinta and Alex had no knowledge about his disability. The diagnosis was a 'huge shock'.

Shelley, Michael and Gisha

Shelley, Michael and Gisha live in regional NSW. Gisha is almost 2 years of age, has cerebral palsy, epilepsy, an intellectual disability and is blind due to a brain injury at birth. Gisha is unable to move independently and is dependent for all her needs. The

family are 'reasonably comfortable' on one income and can afford the goods and services Gisha requires 'most of the time'.

Amy and Angus

Angus is a four-year-old Indigenous foster child with cerebral palsy. His foster family includes Amy, his foster mother, his foster father and three foster siblings. He has lived with his foster family since he was thirteen months old and there is a court order stipulating he remain with them until he is 18 years of age. Angus, his foster father and siblings are Aboriginal. The family are 'reasonably comfortable' on one income and reported being able to afford the goods and services they need for Angus because of the family's income, private health insurance and government supports.

Liana, Zach and Ian

Liana is a sole parent with four children living in a rural area. Receiving government benefits she is 'just getting along' financially and can only 'sometimes afford' the goods and services needed. Two of her children have a disability – Zach is 7 years old and has a global developmental delay and Ian is 5 years of age and has non-verbal autism. Hannah is the eldest child at 8 years and Paul is the youngest child at 3 years of age. Three of Liana's children attend the primary school in the nearest small town (45 kilometres from their home). There are no resources or services where they live. Liana's closest child care support is her ex-partner who lives next door. However, all daily care and responsibility for decisions regarding the children rests with Liana.

Abbey and Ben

Ben is the youngest child in a couple family with three children. He is 3 years old and his mother, Abbey, describes him as 'very curious, very friendly and affectionate'. Ben has hemiplegia, cerebral palsy and developmental delay as a result of a stroke after birth. His brothers are 8 and 11 years of age. The family live on one income and government benefits. They reported being financially 'reasonably comfortable', but can only 'sometimes afford' the goods and services Ben needs.

Margaret, Mark and Georgia

Margaret is a sole parent with five children (13 year old Ryan, 11 year old Emily, 5 year old twins Mark and Georgia, and 4 year old Tom). Mark has autism and Georgia has Asperger's Syndrome. Their eldest brother, Ryan, also has Asperger's Syndrome and has been diagnosed with bipolar disorder. The family live in a small rural town, are 'just getting along' on government benefits and can only 'sometimes afford' the goods and services they need. Mark and Georgia started kindergarten at their local mainstream primary school in 2007. Mark has a full-time teacher's aide because he runs away and Georgia has support two-and-a-half hours a week.

Karen and Rachel

Rachel is almost 3 years of age. She lives with both parents and one sibling in a regional town. Karen, Rachel's mother, reported that the family are 'just getting along' on one income and government benefits and can only 'sometimes afford' the goods and services needed for Rachel. Throughout the interview, Karen talked repeatedly about the financial stress the family are under. Both parents are in good health. Rachel was diagnosed with Tuberous Sclerosis 11 days after she was born. She has epilepsy and low muscle tone.

3.2 Stakeholder Interviews

Key stakeholders were identified by the research team in close collaboration with the Disability Policy and Research Working Group's project Steering Committee. The stakeholders include representatives from advocacy groups, service providers from government, non-government and private organisations and government officials at the policy level.

The primary method of recruiting stakeholders was via contacts provided by the Steering Committee members of each state and territory. Initial contact was made by committee members and the research team followed up by email and telephone. Stakeholders from each State and Territory were identified and contacted, with the intention of interviewing stakeholders from each jurisdiction. Where state or territory representatives did not recommend key stakeholders, the research team identified and recruited individuals via email introduction with telephone follow-up. Interviews were conducted by telephone in March and April 2007 and were of one hour or less duration.

Description of stakeholder interviewees

Contact was made with 17 potential stakeholder participants, of which ten consented to be interviewed (see Table 3.2). Two participants requested the participation of colleagues, resulting in a final total participant number of thirteen. The final sample obtained includes representatives from four states and two territories, and Australian Government stakeholders. Ten participants were from government organisations (reflecting the primary recruitment method) across service development, service provision, policy development and various management responsibilities. Two stakeholders were from family advocacy organisations and were parents of children with disabilities. The final stakeholder was from a non-government service provider.

Table 3.2: Service provider participants

Role in organisation	Service sector	Service location
Project development	State Government	Tas
Service development	Australian Government	Australia
Family representation & advocacy (and parent)	Advocacy	NT
Programs management	State Government	QLD
Service development	State Government	QLD
Family representation, advocacy and leadership development (and parent)	Advocacy	NSW
Management of Policy & stakeholder liaison	Australian Government	Australia
Training in Inclusion and professional support	Govt service development	ACT
Director, respite care	Service development & provision (NGO)	SA
Performance and quality control; management	Government	Tas

The perceptions of family resilience provided by stakeholders reflect their professional perspective. Those working from the policy level gave broad views on the service landscape; those who worked face-to-face with families offered insights into their day-to-day experiences and how these interface with services provided to them. Stakeholders from advocacy organisations were also parents and had held related employment in the recent past. They were thus particularly valuable to this project, given their unique perspective across these domains.

The groups of stakeholders covered a range of supports and services relating to family resilience (see Table 3.3). Government officials' responsibilities spanned the range of areas elicited, with the exception of advocacy and representation, and empowerment and leadership training for families. Advocacy groups and service providers and developers were targeted to their specialist areas. Respondents of all stakeholder groups listed referral, information provision and professional training and support as being within their remit.

Table 3.3: Responsibilities of stakeholder groups

	Advocacy groups	Service providers & developers	Government officials
Macro-level policy development			x
Service-level strategy development		x	x
Referral	x	x	x
Information	x	x	x
Direct funding			x
Direct service provision		x	x
Advocacy, representation	x		
Empowerment, leadership training	x		
Professional training and support	x	x	x

The data collected for this study offers rich description of the day-to-day matters and concerns of families that stakeholders become familiar with in the course of their work. It describes the services and supports that stakeholders are involved with that assist families to enhance their resilience. This data cannot give a statistically reliable indication of the number or distribution of family experiences, or of the services available or accessed. The strength of the data provided here is that it describes the *issues* associated with the services and supports available to families related to resilience. The key responsibilities individual stakeholders held are described below (and is summarised in Table 3.2).

Advocates

Two respondents represent families with a child who has a disability and advocate for them. The services provided by family advocates primarily focus on parental support, information provision and referral and advocating on behalf of families at the systemic level, such as service development and government policy. Both advocates regularly make submissions to government inquiries and reviews. The NT advocate has also 'gone in to bat' for families with children in mainstream schools, to encourage inclusive practices. Both advocates listed various activities undertaken to promote leadership and skills acquisition among families themselves – creating a stronger, more diverse advocacy base.

Service providers and developers

Three respondents provide services directly to families, or support or train other service providers who do so. These respondents all have immediate and extensive knowledge of families who have a child with disability. Two respondents work in Government organisations, but given the direct experience they have with families' situations, their responses reflected those of non-government service providers. Two respondents are involved in respite care services and one provides professional support to child care services concerning inclusive practices.

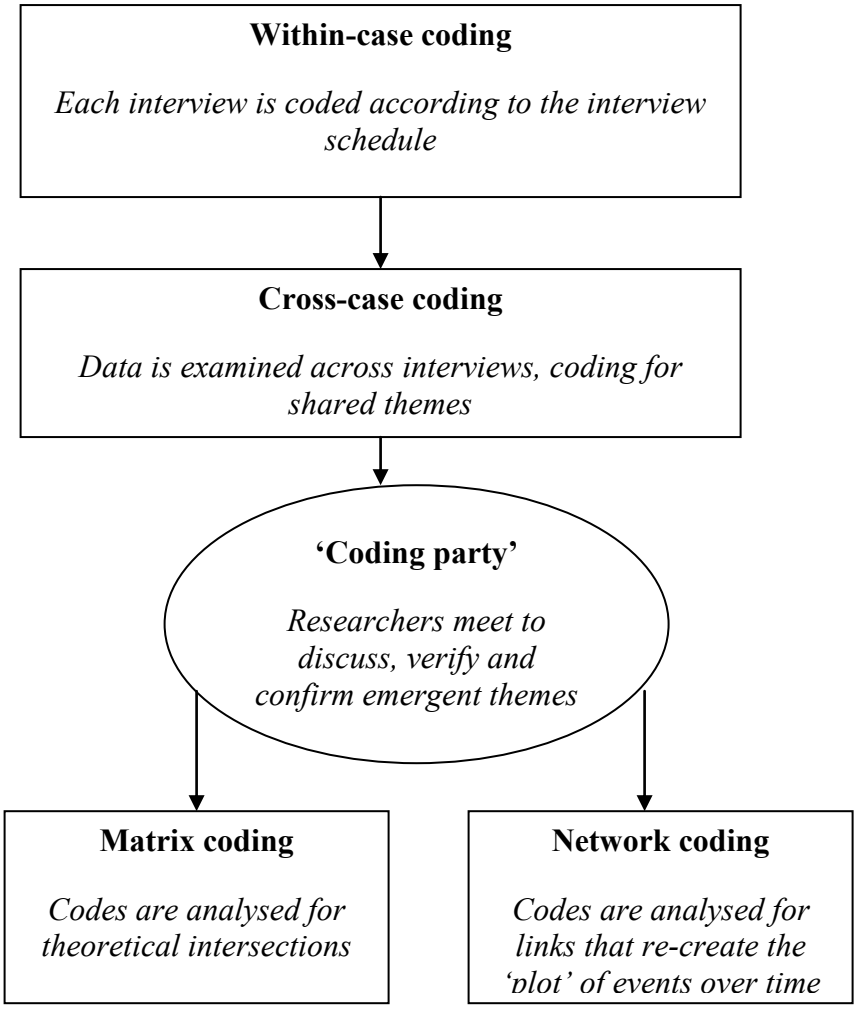
Government officials

Government stakeholders work in policy and project management in a number of disability and family branches. Five respondents were from State-based offices (including a group interview of two); four (including one group interview of three) were from the Australian Government. Some stakeholders' responsibilities were primarily for funding supports and services; some were involved in State-wide policy development; others were closely involved in the development of service delivery models and strategies and rolling them out to services. In some instances, these were pre-established criteria and at other times, they were developed in collaboration with relevant stakeholders and interest groups.

Data Analysis

Data from the family and stakeholder interviews were analysed according to the method presented in Figure 3.1. This method was derived from a number of sources (Miles and Huberman 1994; Bazeley and Richards 2005) and tailored to the current project by the researchers.

Figure 3.1: Analytical method



4 Understanding Family Resilience

This section aims to further develop how family resilience, where families have a young child with disability, is understood. It triangulates data from the literature and family and stakeholder interviews to explore the process of family resilience, how families where a young child has a disability function, the factors (resources and strengths) that protect families and issues that threaten resilience.

4.1 Resilience Research

The study of resilience emerged in the early 1970s (Masten 1997). Resilience is having the ability to function effectively or positively 'in adverse circumstances' (Masten in Schoon, 2006: 7). It was, and still is, predominantly studied in relation to disadvantaged children (Guralnick 2000; Schoon 2006) in terms of trying to understand why some children who have experienced adversity fare well, while others do not.

Childhood resilience is about 'the process of', 'capacity for' and/or 'outcome of' children successfully adapting 'despite challenging or threatening circumstances' (Masten, Best and Garmezy in Howard et al. 1999). The literature bases childhood resilience on a complex interaction between parenting factors, a stable and safe home environment, and an influential adult outside of the home (McCubbin et al. 1997:3-4).

Compared to childhood resilience, little is understood about resilience in adulthood (Bartley 2006:12). Two major factors that have been found to help build resilience in adults are paid work and a united family, which are more likely to increase satisfaction, well-being, health and social networks. Family-friendly work practices may also assist, along with easy access to child and health care and active participation in social networks.

Factors that may place an adult at risk of low levels of resilience are sole-parenting, divorce and unemployment (Bartley 2006:12-13). While divorce is a risk factor, separated or divorced families can experience resilience. Greeff and Merwe (2004:59) found that support from family and friends, open communication with family, work and financial security promoted resilience in divorced families. Silberg (2001:57) found co-parenting practices could also protect sole-parents from poor outcomes.

Although resilience is primarily applied to individuals (and mostly children, rather than adults), much of the resilience literature, is based within Bronfenbrenner's Ecological Model (1979). This model acknowledges the role of families and communities in promoting resilience: resilience is based on individual characteristics, the family environment, the community a person lives in and their access to and experiences with services and supports (Schoon 2006:1-2). Therefore family functioning and family resilience plays an instrumental role in a child's developmental outcomes 'regardless of … disability status' (Crnic and Stormshak 2000:209,211).

4.2 Families where a child has a disability

All families, regardless of whether the family includes a child with disability, often have positive experiences and face challenges and demands. Parents who have a child with disability report feelings of love, happiness and hope, but also challenges (Dobson et al. 2001; Kearney and Griffin 2001; Marsh 2003). Some families where a child has a disability experience additional demands and are more likely to experience increased risk and vulnerability than other families. Without adequate supports and services, these families can experience significant stress. The process of resilience – how families meet these stressful circumstances – is relevant to all families, especially where a child has a disability.

Resilience is only applicable to individuals and families if they have been exposed to an event or situation they perceived as unusually stressful or traumatic. It is important to understand the stressful circumstances some families who have a child with disability can experience. A child with disability may require more parental assistance and supervision within and outside the home, than a child who does not have a disability (Bain 1998:599; Dobson et al. 2001; Roberts and Lawton 2000). Families with children with challenging behaviours may experience compounded levels of stress (Bain 1998). The extra demands of parenting a child with disability can affect parents' objectives and their working, social and home lives (Dowling and Dolan 2001:21). For example, mothers are less likely to work and fathers have been found to decrease their working hours. This can affect their job opportunities, aspirations and promotions (Bain 1998; Dobson et al. 2001:32).

Workforce sacrifices can significantly affect a family's income. Consequently, parents of children with disability tend to have lower than average incomes (Dobson et al. 2001; Lukemeyer et al. 2000). This is further compounded by the additional costs of raising a child with disability (Lukemeyer et al. 2000). Dobson et al. (1998; 2001) found that it costs between two and three times more to raise a child with disability than a child without a disability; and this only included 'minimum essential costs'. To meet the expense of having a child with disability, parents spend less in other areas, such as on themselves, leisure activities and holidays.

Social isolation is a further problem experienced by some families with a child with disability because of financial, time and respite limitations, as well as a loss of previous social networks and stigma (Bain 1998; Dobson et al. 2001:26-7; Patterson 2002:356). These social, working, financial and other stressful situations can affect family members' mental health. Parents who have a child with disability are likely to experience more stress, lower levels of marital satisfaction, poorer mental health and lower levels of well-being than other families (Gardner and Harmon 2002:61; Patterson 2002:356).

Other family members' lives may also be affected. If support is inadequate, parents may have less time and energy for other family members and siblings may be expected to share some of the caring responsibilities (Bain 1998).

A number of families have difficulty coping with these stressful circumstances. Parents with a child with disability are more likely to be divorced or separate than those who have children without a disability (Mauldon 1992). A 1996 survey of 171 NSW based

families with a child under 7 years with disability found one in four of these families had 'either sought alternative residential care for their child or considered it might become necessary'. For those who had already sought care, 'family survival – physically socially and emotionally – was at stake' (Bain 1998).

Therefore, while parents who have a child with disability report positive experiences and feelings of love, happiness and hope (Dobson et al. 2001; Kearney and Griffin 2001; Marsh 2003), without adequate supports and services, some of these families may also experience significant stress. This report explores the process of resilience to understand how families with a child with disability deal with these stressful circumstances.

4.3 Describing and Defining Family Resilience where a Child (0 - 8 years) has a Disability

Family resilience is not a trait, static entity or an absolute. It is a process that will change over time and exists on a continuum of levels. Family resilience where the family includes a child with disability can be described by three steps: adversity, resources/strengths and adaptability (Muir 2008).

Step 1: The crisis, event or trauma

The family experiences one or multiple situations they perceive as *adverse*. This may relate to the disability, especially in periods of transition, such as diagnosis, assessment and school entry, but not necessarily exclusively. The trauma could be in relation to other family issues, such as illness or separation. The adversity is such that the family is at risk. At the time of the crisis, trauma or stressful transitional event families often experience 'disorganisation, conflict, confusion [and] resentment' (De Haan et al. 2002:277).

This first condition is likely to be applicable for families who have a child with disability, but it also depends on how families perceive situations. Therefore if parents do not perceive their child's disability (or another situation) as stressful or traumatic, then they do not fit within the definition of resilience (Peterson and Hawley 1998:221). However, given the affects of a child with disability on many families (described in Section 4.2), it can be assumed that almost all families living with a child who has a disability resulting in high and/or complex needs meet the first criteria.

Step 2: Using resources and strengths or 'protective factors' to adjust

The family has some *resources* and *strengths* to draw on while trying to adjust to the difficult situation. This stage includes having an outcome that the family can achieve. Family members start to adjust by drawing on supports, resources and strengths from within and outside the family (De Haan et al. 2002:277; Patterson 2002:356). These are discussed in further detail below.

This second condition means that only families with resources and strengths to draw upon can be expected to have the capacity for resilience. Therefore, in supporting a family to strengthen their resilience, fundamental supports need to be in place. Thus assisting families to build a foundation of resources (such as financial support, the provision of adequate housing, access to appropriate services) and strengths (like parental behaviour management and problem solving skills) is the first fundamental step.

Step 3: Reorganisation and recovery

The final step in family resilience is for families to *adapt* the way their family functions and recover from the crisis or event, even though there was a risk that the family may not have adapted. Although the family may have changed the way it functions, patterns of functioning are resumed and the family is able to balance the needs of other family members with the need of the child with disability (Gardner and Harmon 2002).

Families will recover with varying levels of resilience. Families experience resilience if the first two criteria are met and then they make necessary changes to resume family functioning (even though the way the family functions may have changed).

Family resilience where the family includes a child with disability therefore is a process that will change over time and exists on a continuum of levels. It can be described by three steps summarised as adversity, resources/strengths and adaptability.

4.4 Identifying and Measuring Family Resilience

Tools that measure family resilience have been developed and used by researchers (De Haan et al. 2002; Silberg 2001; Orthner et al. 2004). However, these tools are not useful for practitioners working with families where a child has a disability. This is primarily because measurements need to be taken before, during and after a stressful event with all immediate family members (and, since these events are likely to occur on multiple occasions, this three stage assessment would need to be ongoing) and the results require complex analysis. Reliability of these tools can also be compromised by the social context of the test, how the practitioner administers it, and how family members interpret the questions and the purpose of the assessment.

Measuring a family's resilience may also place the family further at risk by reinforcing their vulnerability, limited resources and helplessness. Therefore measuring family resilience may not only be meaningless for service providers, but also damaging for families. Consequently, family resilience experts usually advise against using these measurement tools in a practical setting (Bartley 2006; Silberberg 2001; De Haan et al. 2002).

4.5 Family Resilience and the Interviewees

Stakeholder perceptions of family resilience

When questioned directly about what 'resilience' means to them, stakeholder respondents' opinions largely reflected the literature. They referred to intra-individual and intra-family qualities that get them through times of significant crisis (De Haan et al. 2002), as well as the day-to-day challenges of disability and family life (Morison et al. 2003). Stakeholders' concepts of 'family resilience' also reflected notions of 'bouncing back' (McCubbin 1997:5), equity of access to opportunities and freedom of choice.

While stakeholders recognised that resilience is partially 'about the strength of the individual', they also acknowledged the important role of 'support' (*Australian Government official)*. Resilience cannot be divorced from external supports. Overall, the responses of stakeholders reflected the intrinsic relations between intra-individual and

intra-familial strength and the supports they receive – from their own communities and from the disability and broader service sector: 'In the broad, it means any family having the skills to access the support services they need' *(Government Official, ACT)*. The opportunity to access these services is equally important.

A number of stakeholders (particularly service providers) made mention of the 'natural resilience' (*Family Advocate, NSW*) that many families have. This relates more to the notion of *resiliency* (Patterson 2002:352, 354) as a psychological trait, rather than a process that a family experiences. The social worker also commented that families with children with disability 'take a lot more in their stride, a lot more setbacks'. Some stakeholders were concerned that the new rhetoric of resilience would overshadow what families are already doing, and thus further disempower them. Contrarily, too much reliance on individuals being naturally emotionally tough could place unrealistic expectations on family members and abdicates community and governmental responsibilities to support families.

For the purpose of this research family resilience is as follows:

- A process that includes three steps:
    1. crisis/adversity;
    2. drawing on strengths and resources to adjust; and
    3. adapting and resuming family functioning;
- Stakeholders' perceptions of family resilience reflected this process (capacity to deal with a crisis/daily challenges using internal strengths and external supports - the community, disability and service sectors);
- Stakeholders believe resilience is inherent in families (this attitude could potentially affect whether and how families are supported).

Family case studies: facing adversities and stress

The families interviewed were all going through the process of resilience to varying extents. They experienced numerous occasions of adversity, crisis or very stressful experiences; they were constantly reacting to these situations and having to renegotiate routines and restabilise family functioning.

All of the families spoke of experiencing crisis and adversities. They all discussed very stressful experiences regarding issues surrounding the birth, diagnosis, assessments, emergency and planned hospitalisations, treatments and/or accessing services for their child with disability. Parents, mothers especially, also reported being under stress from a lack of sleep due to the extra demands of caring for their child with disability.

For example, Ingrid was born prematurely at 28 weeks with a hole in her lungs, and was in the neo-natal unit for 3 months. She experienced continuous seizures and significant brain damage. When she was discharged from hospital, her parents, Naomi and Bill, carried an oxygen cylinder with them to resuscitate her when she stopped breathing. This was a 'really frightening' and very stressful period for them. When she was 12-months, Ingrid was diagnosed with cerebral palsy. She is now 2 years old and recently stopped eating, which resulted in hospitalisation to have a permanent nasal-gastric tube inserted for feeding. These are some of the major stressful experiences Naomi and Bill have faced over the past two years and the interview revealed how upsetting and difficult this period of time has been for them.

Financial pressures are another stress for some families. Rachel's parents have been under financial stress since her mother, Karen, was forced to quit work. Karen had to leave work after Rachel's child care centre refused to continue caring for her after she had a feeding tube inserted. The family consequently experienced a sudden drop in income and they are worrying about how they will manage financially in the future. Kelly and Robert were under extreme financial stress prior to Jasmine's birth and after she was born.

Most of the adversity families discussed related to the disability of the child in the family, but other stresses were also identified. Gabby's family were under stress from the behaviour problems of her oldest daughter (prevalent before and after her son with disability was born). In addition to caring for her child with disability, Shelley cares for her mother, who has a mental illness, once a week to offer her father some respite.

Another couple lost a child before their child with disability was born and they are unable to have more children. Shelley and Michael were involved in a court dispute and witnessed the death of four friends in a short period of time prior to the birth of their daughter with disability.

Angus' foster family had also experienced significant stress prior to him moving in. They were fostering a little girl and 'thought she might have stayed' with the family in the long term, but returned to her biological mother:

> The grief that we went through as a family, it was like losing one of your own ... we felt bad as parents for putting that on the kids, I mean, they were extremely distressed.

Therefore families experienced both stresses related to their child with disability and other life events. The day-to-day stresses families experienced in relation to supporting their child with disability are also evident in the following section on family functioning.

Family functioning

Family functioning plays an integral role in family resilience. During the first step of the family resilience process, family functioning is challenged. The second stage involves drawing on supports and resources to re-establish functioning; and the third stage is about restoring functioning patterns (even if they are changed or adapted as a result of the crisis).

Most of the interviewees reported that the family's functioning often revolved around the child with the disability. As the needs of these children changed frequently, the family functioning also needed to be adapted. While there were stable aspects to all of the families' lives, such as work and education, the families interviewed were frequently negotiating the resilience process by changing or adapting their family functioning.

Work and education

Work and education commitments ensured some levels of family functioning remained fairly stable, at least for the family members involved in these activities. In all of the couple families (except one, where the responsibility was shared), the fathers were the primary income earners.

Generally the fathers' working week routines remained relatively stable compared to their partners. However, having a child with disability impacted on some fathers' decisions regarding their employment. Due to the time demands of caring for a child with disability, one father reported having more difficulty running his business since the birth of their child. Another father took a job close to home to decrease his commute time and increase his availability to support the care of his child with disability. Contrarily, Michael remained working in a position that requires him to commute 3-4 hours per day because the family need his salary. They can neither afford to move closer or for him to take a job closer to home that compromises the family's income and money available to access the goods and services their child needs. Although Michael's workplace is very supportive and flexible about him taking time off work, it means that during the week caring responsibilities and stress fall heavily on his wife.

Other families were in similar situations where the father's working commitments required lengthy commutes or working away from the family during the week. For example, one father was a miner and another worked on their farm in a remote area while the family lived in town during the week. This placed further stress and responsibility on the mothers. Robert's job takes him away from the family for long hours during the week. Kelly said that she 'resents that a bit, especially if I have had a hard day'.

Only a few of the women interviewed were working. One was able to work full-time because of the flexibility of her and her husbands' employers. The other two women working did so part-time. For one of these women, her work as a nurse one day a week played an important role in balancing out her needs and providing some stability and routine in her week. The other woman was working in a job she dislikes. It has convenient hours and the family need the money to pay for their daughter to attend child care and 'do what other normal children do'. Two other women had some stable routines with part-time study commitments.

Caring responsibilities

Unsurprisingly, caring responsibilities dominated most routines and how the families functioned day-to-day. Routines for the mothers with young children largely revolve around early intervention and therapy appointments. While there are often specified days for appointments, the list of therapies coupled with essential, unplanned medical appointments, illnesses or behaviour problems, mean it is difficult for families to

maintain steady routines. There is a constant renegotiation of family functioning. For example, Abbey takes Ben to major cities approximately three times a year for medical treatment, which upsets her other children, and disturbs the families' routine, but even when the family are home together, routines and planned events are often cancelled because of Ben's medical problems.

Caring responsibilities and medical problems could also interrupt work and education commitments. The high level of dependency of their children and long list of medical and therapy appointments resulted in one mother quitting work and another giving up her master's degree. For both of these women it was 'too much' to be full-time carers and part-time workers or students, but they were disappointed to give up activities that were for them. Similarly, while one mother wants to return to work part-time 'to get out and do something different', she decided it is impossible because of her son's appointments, therapies and his low immune system. The family are able to make this decision because it is not a financial necessity that she works. These mothers' experiences reinforce the extensive role some mothers take on in caring for their child with disability, the restrictions they face in devoting time and energy into other activities in life and the choices they make in terms of their needs.

Many of the mothers interviewed highlighted the extensive time demands placed on them. Amy, who has three older children without a disability, commented that having a child with disability was 'like having two or three' children to look after. For the families with a child with cerebral palsy, the time invested in therapies includes not only appointments, but also exercises and practice at home. Amy was advised to include three to five therapy sessions at home with Angus every day, but noted with other demands on her time she only manages two or three formal sessions. Yet the reality for Amy, Angus and other families in a similar situation, is that 'everything is therapy': 'every time you see him sitting, every time you go past you sort of check that he's sitting correctly, you've got to be thinking therapy all the time. And when you're giving him something, making sure his arms are reaching out for it'. While the family have accepted this 'whole different life' with Angus, Amy is looking forward to him starting school 'where I've got a couple of days where you're not interrupted, where you're not having to think stretches and his positioning and things like that'. When children are young, it is difficult for family functioning to not revolve around the child's disability.

Once children are school aged, maintaining some routine becomes somewhat easier for some families because some routines are determined by school times. For others, however, this was more difficult. Once her eldest child was school aged, Carrie moved into town away from her husband who works on the family's farm. This means she is a sole parent of three children during the week. Living in a rural area adds greater complexity to the time and effort of accessing appointments and services. For Carrie, the frequency of accessing these supports has to be decreased. She takes Hank to a regional town (300 kilometres away) for early intervention sessions approximately once a month.

Family functioning case study

The affect of Ingrid's disability on her family has been 'life changing'. Bill works five days a week and is the primary carer for Ingrid on Saturdays when Naomi goes to work.

During the week, Naomi has appointments for Ingrid on most days. Monday is playgroup at a non-government disability service; Tuesdays early intervention and physiotherapy (every second week); Wednesdays audiologist appointment; Thursdays hydrotherapy and a one-to-one lesson in listening skills with a therapist from RIDB; and Fridays includes a paediatrician, GP and/or neurologist appointments and Bowen therapy to develop muscle strength. The family spend Sundays together, when they often meet with friends.

The families interviewed were repeatedly experiencing the resilience processes. They experienced numerous occasions of adversity, crisis or very stressful experiences; they were constantly reacting to these situations and having to renegotiate routings and stable family functioning.

Family adversity, functioning and resilience:

- Families all described experiencing the resilience process;
- Families experienced many periods of adversity (both related and not related to disability); and
- They were constantly renegotiating family functioning as a result of reacting to changing circumstances in relation to their child's disability.

Protective factors: resources and strengths

The resources and strengths families have to draw on are essential in assisting them to maintain resilience: to overcome adversity, to adapt family functioning and re-establish normal routines. The literature highlights four important factors for families where children are young and where a child has a disability: the ability to solve problems and balance relationships within the family, family hardiness, social support and routines (Muir 2008). Other important resources and strengths for families to draw from are hope and flexibility, financial management, truthfulness, empowerment and spirituality or meaning (Gardner and Harmon 2002; Morison et al. 2003; Parker 2001; McCubbin et al. 1997; Patterson 2002).

Problem solving

Problem solving includes managing interpersonal relationships within the family so that tensions and conflicts can be solved (Gardner and Harmon 2002; McCubbin et al. 1997; Parker 2001:82; Patterson 2002). All family members interviewed, except one, identified good communication as a strategy for solving problems within the family. As one mother reflected, 'Communication is the biggest thing. We've always just shared everything, and been very open'.

These discussions occurred between partners and partners and children. Only one parent noted that she does 'not get involved' in the conflicts between her children, 'Most of the

time I say, "Unless there's blood or broken bones, I don't want to know".' This parent found it difficult to identify strategies the family had for solving problems.

The families' belief that they have the capacity to solve problems was often determined by whether they felt the problems were within or outside their control. Karen explained that she and her partner 'work through' most problems, but 'sometimes there is no answer. Like, the problem, the conflict at the moment is, how are we going to survive [financially]?' As mentioned above, the family's income was significantly affected after Karen had to leave work to care for her daughter.

Balancing family relationships

Balancing family relationships involves being able to meet the needs of all family members, not only the child with the disability (Gardner and Harmon 2002; McCubbin et al. 1997; Parker 2001:82; Patterson 2002). This was a challenge for most of the families interviewed. The hierarchy of meeting family members' needs was generally addressed in the following order: the child with disability, siblings, individual parents (often the father first) and couples.

In all situations the mothers were the primary carers for the children. In a few situations, there was a clear delineation of roles. One father explained, 'I always takes care of business and providing financial security [and my wife] is free to focus on family and [our daughter's] needs'. Therefore when extra caring demands were placed on them, women in these situations often absorbed the extra responsibilities, leaving them little time for themselves. As one mother pointed out:

> I've always been the one who does everything with [our daughter with disability], so in terms of that, I feel like [my husband] could do more. Every time she goes into hospital, I'm the one who goes there, and I'm the one who stays there, and I might be in hospital for two days.

She added that if she informs her husband in advance, he will look after the children, but these are for random events, such as a haircut, not regular occurrences.

In other family situations, fathers took on more responsibility to provide their partners with time away from the children. Bill and Naomi believed they balance their needs well with caring for their daughter. Naomi works one day a week and goes to the gym three times a week while Bill takes on the caring responsibilities; and Bill spends Friday nights with his friends watching the football. Bill stated that he would like to be home more to help care for their daughter, but they cannot afford for him to cut back on the hours he works. Shelley similarly noted that she goes to the gym and to a singing group, while her husband has recently joined a band.

However, what is not being met for these families is spending time together as a couple. This was a common complaint from the couple families interviewed. While Jacinta and Alex recognised that this is 'a normal problem for new families', it could be more pressing for families where a child has a disability because of the additional demands required in baby-sitting. Kelly and Robert felt that the most effective way they could

capture 'valuable time for relationships and re-connecting as a family' was when they were away on holidays.

Therefore for couple families with resources to have holidays or social support, such as shared child care, it is easier for parents to pursue their own interests. This was much more difficult for sole parents. Gabby felt that she 'works very hard so that everyone [her children] gets what they need', but is aware that she does not have any free time for herself.

Addressing the needs of siblings was prioritised, but parents also found this to be a challenge because of the time required to care for their child with disability. All of the mothers reported that their other children 'miss out' in terms of receiving sufficient attention and having their needs met. Abbey commented that her 'two older children want more attention than they get' and, as a result, she believes their behaviour problems at school are related to attention seeking. Liana highlighted the added problem for siblings living in rural areas because it was difficult to assist older children to socialise with friends and participate with their peers in the community. While Liana's oldest daughter wants 'to go to friends' places' and spend time in the nearest town with her friends, as a single parent, Liana has difficulty finding the time to transport her to and from the town.

Parents attempt to spend time with their other children when these children 'don't have to compete' with their brother or sister with disability. For example, while her son with disability is at preschool, Liana volunteers at her other son's primary school because it is the only time she can spend with him away from his siblings.

Some parents are battling to balance instructions from therapists with the needs of their other children. Carrie, for example, has been instructed to give Hank five hours of daily therapy, but she does not provide this level of therapy because her other children 'also have needs'.

The other issue raised by three families in regard to siblings was their role as young carers. The supportive caring roles siblings play are an important resource for parents, yet parents are also mindful of the responsibility and time constraints this can place on their children. Margaret, a sole parent, recognised that her two eldest children are becoming 'young carers' and missing out on aspects of their youth because 'everything revolves around [their siblings with disability]'.

Another mother noted that the older her children become the less she could rely on or ask from them, especially as their schooling demands increase. As Amy explained,

> Previously you were able to rely on them a little bit, even just to do stretching and that with Angus, but ... with the stages of schooling that they're in, Year 10 and 12, ... even to ask them to do the dishes you know, do I call them away or do I not?

Yet she acknowledged that they need to balance the 'responsibilities in the family life' with their schooling and social lives.

In contrast, Liana was concerned that her eldest daughter was taking on too much of a caring responsibility. Although Liana did not intend for her daughter to have a caring

role, 'a lot of it ... landed onto her shoulders' and, consequently Liana worried about her playing 'the mothering role too much'.

Families had difficulty balancing the needs of each family member. Balancing individual needs was easier for couple families with access to resources, but they too had difficulty achieving this. Mothers and sole parents were most likely to compromise their needs in an attempt to meet the needs of other family members. Parents were particularly concerned about balancing the needs of each of their children. Most felt that the needs of their children who did not have a disability were compromised because of the caring demands of their child with disability. Once other children were older, parents were grateful of caring support, but also worried about their children becoming young carers.

Hardiness/durability

Another protective factor is having a family that works together in difficult times. All families could identify some emotional strengths and tangible strategies that they believe make their families durable. Traits such as being 'cohesive, self-sufficient, optimistic' and 'in it together' were mentioned. Couples reported having strong relationships that are 'lovable, close and affectionate'. Parents also drew on the strengths of other family members and the benefits for their other children:

> Our little boy, the way he copes and everything I guess makes us strong too; he just loves her [his sister with disability] to death. When we come in the car to pick him up in the afternoon, he's straight in to give her a cuddle, he doesn't worry about Mum!

While Margaret had difficulty identifying the durability of her family, she noted that having children with disability benefited her other children: 'The kids understand other kids with disabilities, so they're more accepting'. She identified a range of tangible strategies members of her family use to deal with stress: Margaret attends support groups where she can 'talk with other people that understand'; her children listen to music, relaxation CDs and read.

Not all families believed they were durable and, in some cases, partners did not always agree about the family's hardiness. The mother of one child was adamant about the family's durability, but her husband maintained 'we're not as strong as we'd like'. Two mothers reported that their families are sometimes able to endure difficulties and other times not.

Margaret felt that her family was not 'totally strong or tough' and 'there're times where we could crumble as a family'. She felt that her children, who did not have disabilities, sometimes felt frustrated by their family's situation: 'I think some days they'd like to forget they've got a brother [with disability] and just be a kid and go out and play'.

Karen felt that as a family, 'we're together for the long haul', but she was unsure if the family were durable: 'I don't know; it's hard. ... I guess we don't have a choice in certain things, so you just have to go along with it, and that's the way we kind of feel'. This, and Karen's other comments throughout the interview, suggests that the family were able to endure difficulties.

Families' perceptions of their durability varied between and within the family units. Yet all families identified either emotional strengths or tangible strategies they use to in times of stress to help make their families durable.

Social support

Maintaining relationships with relatives, friends and others to keep up social interaction, avoid social isolation and ensure a network of people who can provide practical and emotional support when required can also protect families. Adequate social supports have also been found to improve parenting practices (Peterson and Hawley 1998:222). Social supports include participating in social and recreational activities in the community, both as individuals and together as a family (Gardner and Harmon 2002; McCubbin et al. 1997; Morison et al. 2003; Patterson 2002). Accessing government and community supports and having effective relationships with professionals is a further component of this protective factor (Bartley 2006:4-5; McCubbin et al. 1997; Patterson 2002:357).

Informal support from extended family members and/or friends is a common source of support for most of the parents interviewed. This support ranges from emotional to practical support, such as financial assistance and child care.

Sources of social support

All of the couples cited each other as their main emotional support. They generally reported friends or extended family as the second most common supports and thirdly support groups, such as on-line or community based disability specific groups. The sole parents interviewed rely on friends, extended family and services for their emotional support. Two sole parents, however, appeared to be dislocated from their local communities because they were not emotionally or socially linked with other members of their community.

The women in couple families (with the exception of one) were able to readily identify at least one source of emotional support besides their partner. However the fathers involved in the interview process reported not having anyone other than their partners to talk to about issues raised by having a child with disability.

All except one interviewee identified family and/or friends who provide some practical and/or emotional support. While four of the eleven families interviewed acknowledged that they receive enough support, the other seven families stated they did not get enough. Nine of the families agreed that they 'very often' or 'sometimes' need support but cannot get it from anyone. This demonstrates that even those families who have informal support available cannot rely on that support when they most need it. This is an important issue for resilience and service provision; families with informal contacts still need extra support.

Only one interviewee reported receiving support from her and her husbands' extended families. She is to able to call on her mother and step-father, who live five minutes away, for help and she receives daily emotional support from her mother over the phone. The other interviewees who received family support reported only being able to rely on one-

side of their extended families. Fear, a lack of behaviour management skills, geographic separation, poor health and a preoccupation with their own responsibilities were some of the reasons the interviewees gave for their extended families' lack of support.

Four interviewees receive very little or no support from their families. Two only receive emotional support because of geographic isolation. Naomi's family also live some distance away, but she does not use them for emotional support because she does not want them to 'worry' about her. Her partner's family live close by, but are not willing to provide any practical assistance. Naomi explained that his family informed them that 'if Ingrid was normal, we'd look after her sometimes'.

Friends were less likely to be primary supports for most of the interviewees. Some interviewees were reluctant to ask friends to help with child care for their child with disability because of the extra demands of care, their own family responsibilities and lack of awareness of how to treat and care for the child with disability. Friends were helpful emotional supports and babysitters for other children. Only one interviewee described a situation where friends in the local community baby-sit the child with disability. Another interviewee lost touch with her friends after leaving the workforce to care for her daughter in a full-time capacity, which means she has also lost a number of emotional supports.

Gabby gets neither emotional nor practical support from any of her family. She also has no friends, but her neighbour will occasionally come over if the children are 'a bit wild' and help her settle them down. Gabby had the least informal supports of any of the families interviewed.

Stability of support

Even where practical support was available from one side of the family, there was some anxiety around the permanence of this support. Robert and Kelly, for example, occasionally leave their children with Kelly's father, but at 80 years of age, this is 'increasingly hard for him'. While Carrie's parents moved from a coastal area to support her family in a rural town when her child with disability was born, they are missing their hometown and are considering returning there at the end of the year.

Karen's parents live 150km away and so provide only occasional support. Her mother-in-law lives within walking distance and 'takes Rachel whenever I need her to', but this too is a short-term solution because Rachel requires significant lifting and her grandmother has bad arthritis.

The research found that families draw on a range of informal family and friend supports for emotional and practical assistance. Interestingly, most of the families interviewed who are well supported by extended family and friends still reported requiring extra support. In addition, even if parents are well connected with families and friends, this does not always translate to them using these connections for emotional or practical support. Fathers and sole parents are more likely to be lacking emotional support, than mothers in couple families.

The informal supports families have to draw from work as a protective factor in collaboration with formal services and supports. The formal support families' access are described, discussed and compared in Section 5.

Routines and family times

Another critical protective factor is having routines, such as meals together, bedtime and other rituals, and spending time together to acknowledge and celebrate special occasions, such as birthdays, religious events or family traditions (McCubbin et al. 1997; Patterson 2002). All families interviewed had periods of time they spent together, such as over meals, at church, going on picnics or holidays and doing other family based activities.

While spending time together was found to be beneficial for families, it could also present challenges, conflict and/or stress if activities were affected by the child's disability. Behaviour problems limited the capacity of some families to interact socially or attend certain community events. Parents restrict the places families attend for social events to ensure there is no danger to their child. Robert and Kelly, for example, often either do not attend social events, or leave early to 'minimise the risk' of their daughter running away or acting aggressively with other children.

Couples are more able to balance weekend activities for the range of their children's needs because they can split up responsibilities. Karen's husband, for example, takes her eldest son motorbike riding, while she looks after their daughter. Any activity they do as a family, however, requires 'planning around Rachel', which means they often have to decline invitations to social events.

Where older siblings can take on caring responsibilities, families have greater flexibility to participate in activities they might have previously been restricted from. Margaret, for example, explained that while they cannot take Mark shopping, she can get out with her daughters on the weekend if her eldest son cares for Mark. There are, however, limits to the activities the family does altogether. While they go to the park, Margaret will not take them to places where they are expected to be quiet, because Mark 'doesn't understand you have to be quiet' or to large, crowded events, because he runs away. The types of activities the family does together are restricted because 'unless Mark can do it, we can't do it. So, it's definitely a struggle, definitely not balanced'.

The sole parents were more socially isolated and disconnected to their communities because taking their children, including their child with disability, out on their own was difficult. As Liana explained, 'I find taking them all out can be quite difficult ... I very rarely take them to events on my own … because it's just too hard'. The only time she takes them out is if her ex-partner goes with them.

Hope and flexibility

Hope and flexibility are also very important for families with young children where a child has a disability. Flexibility assists families to adjust and adapt to stressful events and change their functioning and routines accordingly (McCubbin et al. 1997; Parker

2001; Patterson 2002). The flexibility of the families interviewed was evident in the above discussions around family functioning.

Hope is essential in regard to building and strengthening family resilience (McCubbin et al. 1997; Morison et al. 2003:129; Patterson 2002). The nature of what families hope for is not important; what is important is that there is a possibility of achieving the desire or goal (Morison et al. 2003:129). Therefore it is important families hope for achievable goals.

Stakeholders noted that when children with disabilities are going through diagnosis, assessments and disability management plans, their wishes, dreams and aspirations for the future sometimes 'get lost'. Maintaining these and working towards achieving them are considered by some stakeholders to be a central component of family resilience:

> I would add: hope is critical. ... hope is so important when working with young people. When they're young, it's a lot about their dreams, but as they get older, the hope kicks in. The hope that they can actually realise those dreams. (*Australian Government)*

These aspirations translate to future-oriented concrete, practical concerns. These are linked in some way to the child's development and progress. A good practice by service providers that supports families and children to set and achieve goals was described by a social worker from South Australia:

> So we're always asking about the future, what do we need next year? We've had one family swap cars! We do a lot of work with hosts so that they're aware they're growing up. So it may have been fine to change their nappy in the front room when they were three, but is it still a good idea when they're nine? We ask the question "Is this ok for this child?"

Most of the families interviewed have goals or hopes that are indirectly or directly related to their children, such as being able to access required services and supports and for them to get a sound education. Most families hope for happiness, for their families to remain strong and for the needs of individual family members to be met. Some families just hope for a break away from the routine of therapies. Amy, for example, noted that 'looking forward to a holiday just gave me some hope'. One couple wants another child and hopes for a 'normalised family experience'.

While practical support may assist families to set and achieve some gaols there is less hope around goals for financial security. Families have financial gaols, such as being able to afford to move from a unit to a one story house so that they do not have to carry their daughter with disability up and down four flights of stairs. Reaching financial goals is perceived as challenging, especially where both parents working hours are restricted because of caring responsibilities. One mother explained that one of their family goals is to be able to purchase a property, but she lamented, due to government restrictions, 'you can't do that on a carer's pension'. This is a strong example of how accepting

government support by necessity (due to lack of child care options and therefore an inability to work) can place limitations on the long term goals of families.

Financial management

Financial management is not specifically mentioned by researchers examining family resilience where a child has a disability, but McCubbin et al. (1997) include it as crucial for a family with young children. Given the financial stress many families with a child with disability experience (Muir 2008), the high costs of disability (Dobson 1998; 2001; Lukemeyer 2000), and the comments of the interviewees (evident throughout this report), financial management and perceiving the families' financial situation as adequate to meet the families' needs is an important factor for families who have a child with disability.

Six families' main source of income comes from the paid work of the fathers; four families main income is from government benefits and the final family relies on both parents' incomes. Five families reported that they are 'just getting along' financially, three stated that they are 'reasonably comfortable' and two are 'very comfortable'. The majority of the families interviewed cannot always afford the goods and services they feel are essential for their child with disability to achieve a reasonable quality of life. Two families can 'rarely' afford these goods and services and five can only 'sometimes' afford them. Of the remaining families, two can afford these goods and services most of the time (however both of these families juggle finances and decisions regarding their spending and income to ensure they are in this position); and the final two families stated they can 'always afford' them (of these families, one couple is distressed that their financial situation may suddenly change; the other are able to afford these services because they both work full-time). Thus financial pressures and managing finances to be able to afford the goods and services needed was difficult for the majority of families interviewed.

Openness

Family resilience literature demonstrated that transparency and open communication between family members and between families and professionals is an important protective factor (Gardner and Harmon 2002; Morison et al. 2003; Parker 2001).

Most parents interviewed actively spoke with their children about what their sibling with a disability 'can and can't do'. One family has very good communication where they discuss their sibling's disability and the expectations and responsibilities placed on them:

> We have good communication. [At] different times we'd ask them [children who do not have a disability] whether they felt as if we'd put too much on them, or were requesting too much from them, or in any way felt neglected because he was such a high demand child.

One parent found it difficult to help her children understand their siblings' disability, and two parents stated they do not communicate well as a family. Couples also reported talking 'openly' with each other about how their child is going and about parenting. As the mothers are the primary carers and largely going to doctors alone, they often informed their partners about their child's clinical outcomes.

Empowerment

Empowerment of both partners in terms of their relationship and their relationship with service providers can be a protective factor for families (Gardner and Harmon 2002; Morison et al. 2003; Parker 2001). Carpenter (2000:14) describes empowerment as a partnership between service providers and families where the relationship involves negotiation around decision making and reciprocation. The level of empowerment of the parents interviewed is difficult to judge. However, parents articulated their feelings of control, or lack of, when dealing with service providers. In dealing with difficult services, one couple uses a 'good cop, bad cop' strategy, in an attempt to bring the situation under their control and successfully negotiate. The level of control families feel they have in their relationships with stakeholders is further discussed in Section 5.

Spirituality or meaning

Finding meaning in a crisis or being able to make some sense of an adverse situation can act as a protective factor for families (Gardner and Harmon 2002; Morison et al. 2003; Parker 2001). Only two families interviewed discussed religion and their faith as an important part of their resilience:

> Faith, that's been the biggest thing, I think, because without that ... you sort of thought, "I can't cope". You feel sad for people who, you know, they may not even have the faith in God just to be able to have that strength to be able to handle it.

Another mother's faith in God made her believe that 'God doesn't give us more than we can bear', but was distressed and upset about how difficult their families' lives have been since the birth of their daughter with disability.

Three other families reported finding meaning from the birth of their child with disability. For example, one couple stated that they now 'focus on the value and worth of a person', rather than just on 'money and success'.

For Angus' foster family, finding meaning has been an important part of their journey together. They were only notified an hour before Angus moved in with them that he had cerebral palsy:

> It's all meant to be. He's just blended in beautifully with the family, and just seeing what he's brought us into as well. Yeah, and it certainly gives you a lot more compassion ... You know, you see a child walking with a disability, with cerebral palsy, and you know what it's taken in order for them to be able to do that, you know what's involved. But at times it is draining, just because of the workload and that. But, the thing is, you just have to redirect everything to what he's achieved in that time.

Health

The final general factor McCubbin et al. (1997) cited as important for families was the health of the family members. If adequate support services cannot be accessed or are unavailable, a family member's poor physical and/or mental health has the potential to unseat most of the factors listed as critical in protecting and strengthening these families. All except one individual reported their health as good or very good at the time of the interview. However, one of the women who reported good health believes she 'may be suffering from depression'. A few of the parents interviewed exercise for stress relief, but not all can allocate the time for regular physical activity. Although there were only a small number of men interviewed, the men reported better health than their female partners.

4.6 Issues that Threaten Resilience – Risks for Families

When asked about the risks they see their families possibly facing in the future, none of the families stated that they are concerned that their families will separate or relinquish their child. Families worry about their child with disability getting older and how they will cope with emerging issues, such as schooling, increased weight and being able to carry them, about the time when their children were 'not as cute', future health problems, safety and who will care for their children when they are no longer alive. The foster family are worried about the risk of losing custody of their foster child.

Families are also worried about their geographic location, financial security and access to services in relation to supporting their child with disability. One couple worry about affording to move out of their unit with four flights of stairs to a single level home. Another worried about having to move to ensure 'improved access to services' for their daughter. This would mean leaving their 'tight-knit community' where they are supported and their daughter is 'well known and liked'. A third couple, also identified a need to move to access family support, but this potentially places their careers at risk. Another mother summarised that the main risk her family faces, 'all comes down to money'.

Finally, families worry about their other children. One mother worries that her son will 'not get the attention he needs' because of his sister's high level of dependence and medical needs:

> I try to plan activities and things that are just for him, but at times they are compromised because of [our daughter's] condition. For example, last Friday he should have had a swimming lesson, and I had to cancel it because he was with my sister-in-law because we were up in hospital. ... so in the future, I can see that we might have to say no to special things for him because of [our daughter].

Another mother wants to have a second child, but is concerned about the possibility of having another child with disability and did not believe they could cope with such an outcome. Two mothers are concerned about their eldest children (without disabilities) becoming rebellious teenagers and another two are worried about their older children taking on too much of a caring role, which would threaten their education. A sole parent explained the greatest risk for her eldest daughter 'is not finishing high school'. This risk

will intensify if the sole parent is forced to return to the workforce when her youngest child starts school.[8] Even without working, this sole parent is concerned that her daughter will drop out of school 'very very early' and she struggles between the risks her daughter faces from leaving school at a young age and the inability to raise her other children (three of whom have disabilities) on her own with little support from services:

> It's not as if I'd want to put that responsibility on her in helping, but it's part of being a family, we all have to chip in, and she seems to take on that role as well, because I can't do it on my own.

The families interviewed worry about similar future risks. They are all concerned about potential problems associated with their child with disability getting older. Families also worry about the affect living with a sibling with disability will have on their other children and about financial problems.

[8] She was in the process of trying to get a Carer's pension so she is not legally required to look for work.

Family protective and risk factors:

- Having resources and strengths to draw on protects families and helps them recover and experience resilience;
- Families are most likely to use communication to solve problems and manage interfamily conflicts;
- Most families have difficulty balancing the individual needs of family members because of the time and financial resources required to support their child with disability;
- Couples spend little or no time alone together and sole parents have little or no time for themselves and appear dislocated from their local communities;
- Families are stressed about trying to address the needs of their children who do not have a disability;
- Interviewees identified emotional strengths or tangible strategies they use in times of stress;
- Sole parents and fathers are most likely to lack emotional support;
- Despite all except one family identifying sources of informal emotional or practical support, seven families reported not getting support when they most need it;
- Families sometimes socially isolate themselves because of barriers – financial, behavioural, transport, extensive caring – faced as a result of having a child with disability;
- Family interviewees hope for long-term goals, like positive outcomes for their children, and short-term ones, such as access to necessary services and supports;
- The majority of families can not afford the goods and services they believe are essential for their child to achieve a reasonable quality of life;
- Most interviewees reported sound health; but the interviews reinforced the importance of emotional support for families; and
- Families worry about future access to services, their ability to cope with a child with disability as they get older, their financial security, geographic location and about their other children's outcomes.

5 Service Provision and Family Resilience

Service provision has been found to facilitate the acquisition and maintenance of family resilience. It has also been found to constrain family resilience where service delivery is inadequate, services are unavailable or difficult to access, or fraught with intra- and inter-service difficulties (Muir 2008). The purpose of this section is to integrate findings from stakeholder and family interviews that offer insight into the characteristics of an optimal service provision framework, which supports family resilience.[9]

5.1 Formal Services and Supports used by Families

Accessing government and community supports and having effective relationships with professionals are important protective factors for families (Bartley 2006:4-5; McCubbin et al. 1997; Patterson 2002:357). The families interviewed use a range of formal services and supports which can be categorised into community, disability specific, co-ordinated, medical, therapy, family focused and other government services). All families access a range of medical services, however, there is considerable discrepancy regarding access to other types of services. Two families do not access any disability specific services and two families do not receive any therapy services. Only three families have access to some level of co-ordinated support and there is only minimal access to family orientated supports. The latter includes two parents occasionally seeing a counsellor and four families receiving respite. Table 5.1 shows the range of services people access and gaps in their service provision.

[9] The following Section, Section 5, deals with *how* services can assist families to build and maintain family resilience.

Table 5.1: Current service use by service type and family

	Community services	Disability specific service	Co-ordinated supports	Medical services	Therapy	Services focussed on other family members	Other government supports/services
Jacinta, Alex and Artie	Child care (3 days/ wk)	One disability specific service	Lifestart (physio, group therapy child care aide)	GP; cardiologist; ophthalmologist	Physiotherapy, group therapy		Centrelink (Carer's pension)
Gabby and Brad	Long day care (2 days/wk)			GP; paediatrician	Speech therapy	Counselling	Child protection (older child)
Naomi, Bill and Ingrid		Two disability specific services	Early intervention (therapists and hearing tests)	GP; audiologist; neurologist; paediatrician	Physiotherapy, speech therapy, occupational therapy (OT)		
Kelly, Robert and Jasmine	School	Early intervention		GP	Physiotherapy, OT		
Carrie, Joshua and Hank	Playgroup	Early intervention (1xmnth, 300kms away)		GP (60km away)	OT (60km away)	Respite 4hrs a fortnight (60kms away)	
Shelley, Michael and Gisha	Child care (2x 5hr days/wk)	Two disability specific services	State disability department (case worker – physio and child care aide)	GP; paediatrician; neurologist; ophthalmologist	Physiotherapy; speech therapy; OT chiropractor	Four hours per week in-home respite	
Karen and Rachel		Early intervention		GP; neurologists; cardiologists, paediatrician, feeding clinic	Speech therapy, physiotherapy, OT	Occasional access to a psychologist	
Margaret, Mark and Georgia	School	Family disability service		GP; paediatrician; dentist		HACC domestic support (2hrs/wk); occasional respite	
Abbey and Ben	Preschool (3 days/wk)			GP, paediatrician; specialist doctors	Speech therapy; physiotherapy; OT		
Liana, Zach and Ian	Preschool	One disability specific service		Aboriginal Medical Service; paediatrician		Respite (8 hours every 6 weeks)	
Amy and Angus	Preschool (2 days/week)	Early intervention		GP; paediatrician	Physiotherapy, occupational therapy		Child protection (foster carer)

5.2 Service Providers Facilitating and Hindering Family Resilience

The interviews with stakeholders and family members revealed key areas where services providers facilitate and hinder family resilience. These include transitional periods, the eligibility process and availability of support, service quality and treatment, service co-ordination and holistic support.

Transitional periods

Transitional periods can be understood as shifts in circumstances. They reflect a point in time characterised by a change in need. McCubbin (1997) identified them as the first step in the set of three interrelated conditions that define family resilience. Of services that have been reviewed, the level of support available to families during transitional periods is currently limited (Muir 2008).

Transitional periods threatening family resilience were a common theme raised by stakeholders. They involve disability-specific transitions (diagnosis and assessment), and transitions that all children face, but that are compounded by disability. These include transitions into school, growth and development (such as puberty), care transitions between family and institutional care and transitions into employment and independent living. Transitions pose particular challenges for children, families and service provision. Their outcomes can have far-reaching and long-term effects on family resilience. As an Australian Government official articulated:

> Transitions are a real issue. When the parent becomes aware that the child has a disability, that point of diagnosis. What the doctor says is well remembered and becomes the expectations for the future. These transitional points are the risk areas – birth and diagnosis. It's [a problem] when a person ... isn't picked up and moved into the next setting, such as the transition to school, moving out of the medical model into the social setting, things like that.

As many of the children are young, the birth and assessment periods were the major transition points that have significantly affected the families interviewed. These periods were very stressful for many of the interviewees. Therefore service providers play an instrumental role in either supporting families or compounding their stress.

Carrie had expected to have Hank at her local hospital (in a rural area), but because of his irregular heartbeat they were transferred to a larger country hospital and then flown to Sydney after Hank's birth. Although stressful, Carrie reported that 'the staff were great, and the neurologist was especially helpful explaining what was happening'. Carrie's positive experience in Sydney at the time of Hank's birth has resulted in Carrie frequently coming to Sydney for Hank's assessments and paediatrician appointments.

Contrarily, Jacinta explained that when Artie was born 'the registrar didn't know how to handle telling them' about Artie having Down Syndrome and begun by asking if there were 'unusual features' in either of their families. Kelly also recalled how poor her doctor's approach was in telling them their daughter had Down Syndrome. In both

Jacinta and Kelly's experience, there was at least one individual at the hospital who provided good support and information (a neonatal specialist for Jacinta and a nurse for Kelly). The medical staff were 'incredible' with Shelley's daughter after she was born, but there was no support for Shelley. She felt alienated sharing a maternity ward with new mothers with healthy babies and felt she had to be 'demanding and difficult' to see her daughter in the intensive care unit.

For families with children with autism, there was a struggle to receive a diagnosis. Margaret insisted something was 'different' with Mark to a clinic nurse, but she dismissed the idea. Eventually Margaret demanded to see a paediatrician: 'It was the paediatrician who finally listened and said "Yes, I think you're right". I'd picked it was autism'. Margaret faced a similar 'fight' trying to get her eldest son diagnosed after she realised he was experiencing poor mental health:

> I had to threaten them [health service] that I was going to contact Current Affair for him to be seen, to be diagnosed. They kept saying it was typical adolescent behaviour, without even seeing him. ... Soon as I threatened them with Current Affair, they rang me back within a half an hour, had an appointment that week on a Friday to see somebody. You just, you've got to pull out all the straws, you've got to start playing their game and threatening, and you shouldn't have to.

He was subsequently diagnosed with bipolar disorder. Margaret was frustrated that every public service she has tried to access, besides early intervention, she has 'hit a brick wall' and had to 'keep fighting' to ensure her children get access to the services and supports they require. As a sole parent on government benefits she has to fight for public services because she cannot afford to use private services and supports.

Transitional periods were difficult for families (although the families interviewed focused on the birth and assessment period, which reflects the age of the children). Only two of the eleven families reported receiving good support from service providers during the birth and assessment phase. This is a critical time for families to receive appropriate support and therefore essential in supporting families in the resilience process.

Accessing information and services

Learning about and getting access to appropriate services is an important step in families being able to adjust to having a child with disability (the first stage of the resilience process). Only a week after Jacinta returned home from the hospital with Artie, the Down Syndrome Association visited. This was critical for Jacinta and Alex in gaining access to information about the Syndrome and learning about the resources available to support them.

Jacinta and Alex, however, were in the minority in regard to receiving information immediately after their baby was born. Amy articulately explained the situation a number of families with a young child with disability find themselves in: 'Unless you know the questions, half the time, you're so in the dark ... [because of an] extreme lack of information'. She complained about her state government department of child

protection's failure to provide sufficient information to her family taking on a foster child with disability:

> You would think they would be familiar with disabilities, with the different kids in their care, yet they didn't come forward at all with a lot of information. We felt very, very lost, for a number of months, and very isolated.

Amy added that most of the information she acquired was from other carers or parents of children with disability.

After her son was diagnosed with autism, Liana 'didn't know where to go' or what services she could access. After attending an early intervention centre in her local area, she was linked to an autism association who could provide her with the information and supports she needed.

Margaret was also frustrated that no one informed her what services were available or what her family was entitled to:

> No-one tells you what's around. You have to ask, I mean, I've been here now nearly three years, and no-one told me about HACC. It was only because Mark went to hospital and the nurse there knew Mark was autistic, and said to me, "Have you been down to HACC, you should be getting a cleaning lady come in, or an ironing lady". No one's really out there to tell you about what services you can access.[10]

Similarly, Shelley did not become aware about home care services until her 2 year old daughter was recently in hospital. She lamented that she had not known about this earlier because

> I had like months and months where all I was doing was getting up in the morning, trying to get food into her mouth, before taking her to day care so I could go to work, come back at night, pick her up, try and do the same thing again, try and get her medication in, and I wasn't getting anything done.

For most families, getting access to information about appropriate and available services was a challenge. There was widespread frustration among the families that this information was not provided at the time of the assessment. This did not bode well for families' first negotiation of the resilience process because resources and supports could not be easily drawn upon.

[10] Even when Margaret was aware of services she needed and were available in the community, she could not necessarily access them. It took her three years to get access to a doctor in her regional town and without a doctor she could not get access to a paediatrician.

Eligibility for and availability of services and supports

Families' resilience could also be tested by eligibility and assessment processes to access services and supports. Some families experienced, or continue to experience, prolonged stress when referrals and assessments were/are delayed or repeated applications required. A sole parent interviewee who has no support from family or friends, for example, is frustrated and stressed about her application for respite care through her state's disability department. Shelley has also been involved in an assessment process with the same department for over three months. Three months after applying for ongoing home care support, Shelley is still waiting for her application to be approved or rejected. Shelley described this time lag as 'just typical' of other disability services, which she finds 'frustrating'.

Three families reported having difficulty obtaining approval for funding from Centrelink, meeting application deadlines and getting through the bureaucracy. After filling out multiple forms and standing in a queue for two hours, one mother questioned whether the 'small amount of money … was worth it'. Another mother was 'knocked back' for a Carers' Allowance but after requesting the documentation through the Freedom of Information Act, realised that someone at Centrelink had filled out the form incorrectly. The application was reviewed at the mother's request and the allowance eventually approved. This mother managed to overcome this obstacle because she had the skills and resources to challenge the decision, but she recognised that 'it must be very hard for people who aren't educated and don't know how to find out [information]'.

Families' resilience was also tested when their children were deemed ineligible for services or equipment they believe are instrumental to the child's development or necessary for the family. Jasmine was 'knocked back' by her health service for speech therapy because she was not considered to be 'high needs enough'. Her mother believed there was 'inequity of access', with the limited support going to children 'with more serious challenging behaviour' and 'squeezing out' other children with disability.

Five of the families interviewed are waiting to receive access to a speech therapist for their child with disability; two of these families are also on waiting lists for regular physiotherapist appointments. The waiting lists in rural areas are also a result of the disability department's inability to fill vacant positions in these areas. Kelly is waiting for physio and speech therapy for her daughter Jasmine and is 'furious' about the 'big inequity issue' of service availability in rural areas.

The geographic disadvantage for families living in rural areas was also noted by family advocates based in New South Wales and the Northern Territory. Distance can have a direct impact on service provision and without clear communication and support from professionals, family resilience may be compromised. The Northern Territorian advocate discussed the difficulties for families in rural and remote areas:

> Distance, transport, communication, getting to see a doctor. Here's one example – physio. One person has got a client list of 300. They don't consider how far you've got to drive to see people; you drive all day to see one. And in the wet season it's worse. The thing is, the kids just don't get to see them.

Thus access barriers may prevent uptake of important services and supports.

But even in urban areas some families have difficulty accessing services because of the competition caused by limited places. Shelley, for example, was refused access to supported child care because her daughter, she was told, 'wasn't disabled enough'. As Gisha has cerebral palsy, epilepsy, cognitive impairment and is blind, Shelley believes that the co-ordinator did not want to accept Gisha because her support needs were so high. This experience affected Shelley's mental health and consequently, she waited another year before she considered looking for work and another child care centre.

As the families interviewed have mainly young children, attaining equipment only emerged as a substantial issue for a couple of families. Two families discussed their inability to obtain funding from the Program of Appliances for Disabled People (PADP) for equipment their children needed. Ingrid, Naomi and Bill's daughter, requires a stroller that will support her head and neck, which costs approximately $7,000. PADP informed the family that the stroller was too expensive and would not be funded. When Naomi pushed for an alternative, PADP sent a second hand stroller that was 'old, tired, clunky, and torn and patched together with tape', which did not fit Ingrid. The family are now on a waiting list, which they have been told has 'a big backlog'. Karen's application to PADP was also refused.

The 'fight to get basic services' was shared by most of the interviewees. Naomi is tired of fighting for services and supports for her daughter: 'I resent being treated like a beggar'. She is also upset that despite children and their families needing, rather than wanting, services, if the services are eventually offered some providers 'act like they are doing you a favour'.

Amy found that trying to access some services made her 'feel more frustrated' with her foster son's situation and consequently she concluded, 'sometimes you just feel like being left alone'. It took Amy over a year and 'a lot of head banging' to get approval to have their shower modified. Parents noted that the ongoing fighting to get access to services made them 'more assertive' or 'pushier'. But this also increased the family members' stress levels. While some are well educated and well resourced and could 'negotiate the system', this is not necessarily the case for all the interviewees and it is reflected in their use of services.

There was also some frustration that families or their child's health had to be in crisis before support was provided. Karen explained that when she was desperate to receive assistance she could not get it, but once her daughter's physical health deteriorated, and she required a feeding tube inserted, the family was given access to additional supports:

> I was stuck in no man's land ... I was having all these feeding problems, and it might take me an hour just to get a teaspoon of medication into her. And I wasn't able to get any help ... but now, as her condition has got worse, I've got more opportunities opening up [such as] the feeding clinic and paediatrician. And I'm more eligible now for a carer's pension.

The availability of services in rural areas was a cause of stress for families and imposed significant financial and time constraints. For Carrie, the closest services are 60 kilometres away, but these services are not as convenient as driving to a larger country town where she can stay with and have the support of her parents. Yet, with $15 a trip isolated travel allowance only a small proportion of her costs are reimbursed. Kelly drives Jasmine 600 kilometres to access an 'essential' physiotherapist and an early intervention centre. Attending this service is a considerable expense, but Kelly believes it is critical for the Jasmine and the family's wellbeing: 'I don't know what we'd do without them'. She is frustrated that the state government has not filled the service gaps in her local area and that the limited support that is locally available employs 'poorly trained' staff: 'the government never lived up to its deal of closing institutions in return for providing community based support services'. Abbey is also disgruntled with the limited resources in her local area and the 'long waiting lists'.

Two of the families from rural areas are prepared to travel for some services. They are primarily concerned 'about government commitment [to service delivery], not distance'. This is a consistent concern for families; they are eager for an increase in the availability, quantity and quality of services. Parents are upset that their children are, or were, deemed ineligible for service provision, not because they do not need the service, but because there are other children assessed as more needy. Therefore at a crucial time of early childhood development, without services their child can increasingly fall behind. Karen explained that while her Early Intervention service is very good,

> It could be improved, … more could be offered, but it comes back to funding. They could have a physio there more often. They could have an occupational therapist in every week, they could be doing different programs like a music therapy or something, but they just don't have the funding.

Abbey also wants 'more resources for occupational therapy, speech therapy and physiotherapy' in her area.

Eligibility and assessments for services and supports repeatedly stresses many of the families interviewed, which negatively affects the resilience process. Delays with applications, appeals and rejections place families under considerable stress. They are frustrated by repeatedly having to demonstrate their child's level of disability and their need for services and supports. Approval for services is further contentious when families are rejected or placed on long waiting lists because their child is not considered to be high needs enough, yet the families believed they are critical for childhood development or family wellbeing. This is tied to dissatisfaction around the limited availability of services and the reactive nature of service provision, where support often only becomes available when families are in crisis. This is an area that requires redress if services and supports are to effectively help families to strengthen, build and maintain their resilience (how this can be done is discussed in Section 6).

Service quality and treatment

Even where families are aware of services, eligible for them and can get access to them, the treatment they receive from frontline staff and quality of service their child gets is instrumental in effectively supporting families in their resilience process.

Most of the families have established positive, trusting relationships with their general practitioner and paediatricians. These medical services play an important role in supporting families. The two families with Indigenous children are very positive about their relationship with their local Aboriginal Medical Service and noted that this service actively refers them to appropriate service providers and facilitates access to key information.

Access to mainstream child care where families can be assured of sufficient support from an aide is a very good support for families: 'The [preschool] are really good, they're very helpful'. For Shelley and Michael child care plays an important role in their lives because it provides them with a 'normal experience' of parenting. Their daughter is well supported, staff are 'very welcoming' and their trust in the centres' staff is such that they 'never feel concerned about leaving her'.

Families also feel well supported by some specific disability services. Early intervention is perceived as a good 'one-stop-shop' for some families, which offers some co-ordinated supports and a place to get ideas, solve problems and access counsellors and other families in similar situations. The coordination of supports offered by early intervention is an important part of the perceived value of the service.

Two of the parents reported receiving emotional support through counselling, but such support does not always have to be formalised. A family advocate pointed out the importance of service providers offering emotional support: 'Many services appear to overlook the emotional support required of families. This is not necessarily resource burdensome work: often it is a case of listening while parents 'vent' over the phone'.

Two families are actively involved with the same non-government disability service and drew heavily on this organisation for emotional support and to receive information, assistance with problem solving, emotional support and to network with other families:

> I am also involved with Aspect at [another regional centre about 100 km away]. They sometimes have family outings. If I'm having a real problem with [my son], I just ring them up and they give me information. I was attending their meetings ... I can't always get over there, but if I can I will go. They're really good, actually.

A non-government disability service plays an important role in Naomi, Bill and Ingrid's family. Naomi described the support they receive as 'professional, fantastic and brilliant'. Therefore, where disability services are appreciated for their service quality, they are an essential resource to families.

Families were especially upset and disappointed when disability services did not meet their expectations. One mother was very angry about the response she received when she

first contacted a non-government disability service. The woman she spoke was 'absolutely patronising, cold and detached', left her in tears, and told her that she could only get advice and information if she was referred by a doctor. Four months after the doctor submitted the referral a social worker came to their home asking 'What do you need?' Without adequate information, the family did not know what they needed or what services the provider could offer. They have since received physio, speech and occupational therapy through the disability service, but were disappointed with the quality of physio and speech therapists.

Naomi started to pay for private speech therapy for her daughter because the one provided to them free of charge by a non-government disability service was, according to Naomi, ineffective and unproductive and consequently 'a waste of my time'.

Amy was also disappointed in the quality of publicly provided physiotherapy and, as a result, also now privately pays for physiotherapy for Angus. She was also disgruntled with contact she has had with the same non-government disability service:

> We felt a little discriminated against, just the fact that we were seeing our own private therapist. They weren't very forthright in giving us any information, even in term of access to equipment or anything, they were just very hopeless, actually, just from our own experience ... it was .... very frustrating.

Abbey also found her local cerebral palsy support group to be 'very unwelcoming' and does not intend to contact them again. She also found the publicly funded physiotherapists to be less effective for her son than one they paid for privately. While Amy and Abbey have private health insurance and can afford to access private physiotherapists for their children, Karen is not in a similar position. Her daughter currently receives only one physiotherapy session every three months:

> If I had money, I'd be having weekly physio type sessions. ... I can do a lot of it, but I do feel that sometimes there is more that she should be getting. And I can't afford it, it's $80 an appointment.

Once families found therapists and other service providers who were effective, they were anxious to keep them as part of the family's support network. These experiences demonstrate not only the important role organisations can play, but also individuals. As Abbey identified, it is 'the people ... not the service they work for' that has resulted in her positive view of the service her child receives.[11] Amy too noted that great support is 'not necessarily a service thing; it's individuals that work there, how supportive and helpful they're going to be'.

[11] This highlights the importance of developing and retaining quality staff within services and disability specific training for individuals working within the service from the telephone operators to the therapists. This is discussed further in Section 5.

How individuals within organisations work with families is critical to families feeling supported by services. As another mother explained, 'it's just been the individuals who have been exceptional'. An 'exceptional' individual is experienced, well trained, willing to impart information and find out information when requested, communicates openly with the family, and provides families with options. They are willing to link families to other services and, importantly, families can see tangible outcomes, such as improvements in their child's functioning, decreased parental stress levels from increased information, behaviour management and access to services. Families talked about how the very good service providers are not only the people parents could learn from, but they also listen to parents and encourage parental input into service planning.

The level of control families felt they had in relation to dealing with services is also important. Where service providers are perceived as 'well educated, confident and resourceful', family members 'trust their advice' and feel empowered in their relationship.

Some family members proactively try to increase their control of service provision situations. Carrie tries to increase her level of control by researching on the internet before meeting with service providers to ensure she is informed. She believes that 'information is power' and educating herself is the most proactive way to 'fight' for the families' interests. Not all parents, however, have the resources – such as access to the internet and the skills to search it – to inform themselves about their child's disability and possible service options. A mother with fewer resources to draw on, for example, feels she has 'not a lot' of control in relation to service provision: 'You have meetings, but other than that, you don't really have that much control at all'.

Other mothers have the intention of increasing their control over situations but circumstances do not always make this possible. Karen reported feeling like she needs to become 'stronger for Rachel's sake' but sometimes she agrees with service providers without feeling adequately informed because she fears that her daughter will lose the opportunity to get what she needs when she needs it. Similarly, Naomi prevents herself from being open with service providers if she is not happy about an element of the service provided because she 'doesn't want to isolate them'.

Interestingly, another mother feels she has substantial control when dealing with general community service providers, such as the preschool, and those privately employed, like a physiotherapist, but considerably less with disability specific services. Amy described the frustration her family has experienced with poor service provision and the difficult position this places families in because they cannot always reject services and go elsewhere:

> They don't take you seriously sometimes, or [it is] very slow to see anything happen, and quite often I find you have to make phone call after phone call about the same thing. That's very, very frustrating … that's why you just feel like cutting them out completely, and just being left alone. But, you know that you need it. You need guidance, and as he gets older, he's going to need different equipment. So, it has been very, very frustrating, and even now you still feel a little lost … even

> the [disability service] that's meant to be there, that we thought we could find out anything we needed to know, and they weren't helpful at all! So the service that you think really zeroes in on this area you could rely on, and just to find that you have no support whatsoever.

How service providers relate to families and the quality of service children receive is critical to effectively supporting families. Families reported sound relationships with general medical services and were likely to report positive relationships with community supports, such as child care services. Experiences with disability service providers were mixed. Families initially had high expectations of the supports they could receive from specific disability services and where these expectations were met families felt supported, but there was considerable disappointment and exasperation where this was not occurring. Families were likely to report good practice support as coming from individuals, rather than whole services. 'Exceptional' individuals were described as experienced, well trained, effective communicators, who provided consistent and regular follow-up and produced both positive outcomes for the child and the family. Thus family resilience was supported by some practices and threatened by others.

Service co-ordination

Where it was available and effective, service co-ordination could significantly support family resilience. Only three families experience some level of service co-ordination. Shelley was the only family member interviewed who has an active case worker (from the state disability department). This worker co-ordinates Gisha's therapy, child care support and access to other services. This role is important because, unlike other family members, Shelley is 'exceptionally satisfied' with the support from the department and perceives her case worker and other service providers as 'an integral part of the team'. The benefit this has to the family feeling supported is unquestioned because they have no informal support from family members and yet, Shelley was only one of two family members who reported always receiving support when it was needed.

Jacinta and Naomi's children receive some co-ordinated supports from their early intervention centres. For Jacinta's son, Artie, this involves physiotherapy, group therapy and the provision of a child care aide. Naomi's daughter's early intervention centre provides the family with a 'one-stop-shop' of therapists. But Naomi does not believe this level of co-ordination is sufficient. She advocates the importance of a co-ordinator who can provide the range of information families need to know from the time their child is born, or diagnosed, with disability. For example, Naomi is angry that it took her two years to discover the availability of a Carers' Allowance and only became aware, at the time of the interview, about her state disability department's services.

Other family members are keen for service co-ordination to be introduced. Abbey for example, commented: 'It's very frustrating that the physio and OT don't communicate together ... None of them seem to talk to each other – you have to explain everything all over again to everyone'. Robert and Kelly have a departmental case worker for Jasmine who is 'supposed to case co-ordinate'. However, they are currently not supporting the family because of a lack of resources in their local area.

Karen is very particular about the co-ordinated support she requires:

> I guess the support that I feel like I need is dealing with all the agencies and that sort of thing. I feel like I need support once a week nearly, I guess, just with a lot of the ringing around and that sort of thing that I'm doing. I mean, you can phone someone up and they might not phone you back, so you've got to phone them two or three times.

Karen is currently on the department's waiting list for a case manager. Her recent discovery that this role exists reinforces the important role of a case co-ordinator:

> I didn't even know that a case manager, that such a thing existed, until I was in hospital the last time, and a social worker put a referral in for me to get Home Care. ... And the Home Care assessor came out and said "So, who's your case manager?"

As a foster carer, Amy has a case manager through her state government department of child protection, but she too pointed out the need for a case manager experienced in and informed about the disability sector who can 'point the family towards' the services, equipment, networks and therapists they need. Families also pointed out the importance of having a case manager or co-ordinator that had regular contact with the family:

> Because you find you're the one chasing them [service providers] up, you do feel very left alone, and again, unless you know what to ask for, you don't even know what to go looking for. ... Basically [we need a case manager] just giving you information that helps you on a daily basis with managing your child.

Co-ordination is important in rural areas to support families and to change the way services work. Kelly feels that a more co-ordinated approach would assist to address the lack of 'family involvement in policy or partnership initiatives'. She believes that for a co-ordinated approach to work in rural areas, 'a whole of government approach' is needed.

Although not specifically mentioned by families, stakeholders involved in programs with facilitators noted emotional support as being a key service provided by this model of service provision. It was also a key role of service provider stakeholders who maintain a close working relationship with families; and advocates were keenly aware of this task in their 'duty statement' and the importance of emotional support:

> A lot of stuff happening in support is about the practical side, not the emotional. Families talk about the key worker who changes regularly, getting the physios in, the speechies [sic] in. It's all about practical stuff. The important thing is often asking them "Are you ok?" – the emotional stuff *(Service provider, SA).*

In only one situation did a family have an active case manager who facilitates the range of services the family receives. This is perceived to be an incredibly valuable support and a very important factor in this family's high level of resilience. All families are adamant about the need for this type of support. They want co-ordinators who were well trained,

well informed about the disability sector, and effective communicators who can inform them about the services they can access, offer some emotional support and help co-ordinate the range of supports and services they use. Such support may substantially assist to strengthen the resilience of families who have young children with disability (see Section 6 for further discussion).

Holistic support

One of the factors identified by stakeholders and family members that helps facilitate family strengths, and in turn resilience, is holistic support. Interviewees referred to underlying cultures of practice that either embraced the child within the family and the community, or the child's disability. Advocates in particular were well-placed to tease out these issues:

> How having a child with a disability is framed – grief, burden – you go through that, yes, but it sets up a framework that may quash the capacity to move forward. You've got to ask, "When did the deficits emerge over time?" Parents are often sent on a specialist disability path that removes them from the networks they most need… because people with disabilities will be most safeguarded when they have real relationships with people who do not have disabilities *(Family Advocate, NSW).*

Overcoming the 'deficit framework' that this family advocate identified may be achieved by services taking a holistic approach to resilience. For these services, resilience is not served solely by disability-specific interventions. She offered the following question that services providers could ask themselves when seeking to enhance a family's resilience:

> What would it take for your son or daughter to be a valued member of your family, your community? What would it take for a child with very high support needs to participate in local life?
>
> The answer would take myriad appearances within and without the disability sphere, depending on the individual circumstances of the child and her family.

A popular program delivered by Disability Services Queensland, offered this approach:

> Families can also purchase non-disability support of that is going to assist the family, such as home support, domestic assistance, if that will take the pressure off. The program is about building the family's capacity *(Government official, Qld).*

The families with young children with disabilities who were interviewed access very few supports that work to assist the whole family; most just focus on the child with disability. Two mothers occasionally use local counselling services. The most common form of support families received is respite. Four families receive respite care – two of these are in-home respite, while the other two are outside of the home. The in-home respite enables

Shelley to clean the house while a carer spent time with Gisha. For Margaret, a home carer cooks the meal and provides cleaning assistance one night a week, while Margaret bathes, feeds and settles the children. This is a very valuable support for Margaret because it is the one night of the week when her household (which includes three children with disability) is calm and the family spend quality time together:

> Normally they don't sit down at dinner time and eat, it's like fights and they're running around, and I have my dinner late, I can't eat it while they're running around, so Tuesday night's great, ... they'll all sit out there and eat, I have a hot meal and then I get to read them a great story, I get to read several books, and then she does the cleaning up of the dishes.

This support is also very important to Margaret because it was a result of a service responding to her needs, rather than having to fit within an existing inflexible service structure. Margaret also receives respite once a month, where the children are taken out for the day. This is important because the disability service providing it tailors the respite the family's needs. For example, they provide a male role model to spend time with her eldest son after a request from Margaret and take four of her five children on an outing so she can spend some quality time with one of her children. They also provide family outing days, where she can spend time with the children doing an activity they would not normally have the opportunity to do.

The flexibility of the Commonwealth Carer Respite Centre's support has been very important for Rachel's family in assisting them to have a family holiday and access information sessions:

> Actually, Commonwealth Carer Respite Centre have been really helpful. I phoned them up the other day, and told them how we had a holiday booked for July, and how I was going to cancel it, because we can't afford it now, and I'd paid $200 of it, and it was $735 for a cabin at Coffs Harbour for a week. And they're paying the rest of it. And they also paid for me and Rachel to fly down to Sydney last year to attend a conference on Tuberous Sclerosis. So they've been great *(Karen, Rachel's mother)*.

Liana also appreciates the break respite provided her and the family outings. For Liana, the parental contact at a non-government disability service has provided her with an important support group:

> A lot of parents there aren't as judgemental. I don't have to make excuses for his behaviour ..., they understand what it's like, and you're getting to know parents of people with similar problems. ... A lot of the time I can offload on them too, which is really good, and they also on me as well.

Seven of the families interviewed are not receiving any respite care. One sole parent without any other supports is on a waiting list for respite through the state government disability department and is frustrated because she has no indication of when she will receive a break from her four children (three of whom have a disability). Naomi and Bill have used respite care on two occasions but were dissatisfied with the quality of carers sent to look after their daughter. They felt it was a risk to leave their child with workers they felt were poorly trained and unreliable. Bill outlined that they are interested in receiving respite care in the future, but it is important for them to be able to 'trust' the carer(s). Therefore family resilience is not only based on whether the family has access to services, but also whether they perceive these supports as positive for their child and worthwhile for the family.

Community setting

Holistic supports assist families to actively participate in their community and therefore act as a protective factor in regard to resilience. Isolation from the community can be a potential problem for families who have a child with disability, especially for sole parents. The issue of community as a vital factor in family resilience was raised by many stakeholders. Stakeholders discussed the resources that strong communities can provide families and the need to enhance community participation for families.

Coming from a cohesive community was noted as being characteristic of high resilience:

> Anecdotally, what we hear is, they're fortunate being a part of a community – family, local, church – they are well supported *(Australian Government official).*

In the context of child care, an Australian Government official noted that:

> Some services are very good at facilitating networks for families, by setting an example, by modelling and taking a bit of proactive action in their community. Not so much networking events that can fail miserably, but having a management commitment to networking. When that happens, it becomes a hub for a whole range of things.

Given the benefits of community cohesiveness, a number of stakeholders noted that enhancing this also enhances family resilience. For example, where respite care services are family based and children with disability are exposed to new and different experiences, parents feel supported:

> [In respite care, the children do] whatever the family is doing. If they've got a soccer match on, they go to soccer. Family stuff, whatever is happening for that family – if that's ok with the family and with the child. Sometimes it's stuff they wouldn't get to do otherwise. Our aim is not just about respite for the adults, but opportunities for the child too. That's a nice release for the parents, knowing that their child is building experiences *(Service provider, SA).*

Community-mindedness was raised by this service provider, whose respite service relies on volunteer assistance, as a resource that could be drawn upon to enhance family resilience. She noted that they are a 'dying breed'. Those who offer their time voluntarily tend to have personal experience with disability, or are:

> Your 'call to lifers'. We target environments that foster that attitude, churches or church area, some school environments where they have a working curriculum about care and respect. Community-based activities, those who are already out and about in the community to support community stuff (*Service provider, SA).*

Holistic support, where services focus not only on the children with disability, but the child within the family and the family within the community are very important to strengthening families. Families find considerable support and strength from services that enable them to easily spend time together and that provide integration and networking supports.

Service provision – facilitating and hindering family resilience:

- Transitional periods are critical periods where a family's resilience may be tested;
- Families reported experiencing most stress and negative experiences with services at the time of their child's birth and/or assessment;
- Learning about and getting access to appropriate services is an important step in families being able to adjust to having a child with disability;
- Many families experienced difficulty accessing information about appropriate and available services when their child was first born/diagnosed, but also ongoing;
- Families are strengthened by knowledge that their child is getting access to effective services, where some positive outcomes were visible;
- The eligibility process for services repeatedly frustrates families, especially where there are delays with applications, long waiting lists, the need to appeal, or rejections;
- Family resilience is hindered when families are under considerable stress because their child can not get access to a service/support/therapy at a critical time in childhood development, not because they do not need it, but because other children's needs are deemed higher;
- How service providers relate to families and the quality of service a child receives is critical to effectively supporting families;
- Families are predominately content with the service relationships with mainstream health and community services, but are likely to be dissatisfied with some relationships within the disability sector;
- Families feel supported and are strengthened by service providers who are experienced, well trained, resourceful, communicate openly and effectively with the family, and who are willing to find and impart information and provide options;
- The one family that receives co-ordinated support from an effective DADHC case manager is one of the very few families who reported not requiring any additional support;
- Co-ordinated support is an important factor that facilitates family resilience;
- All families are adamant about the need for co-ordinated support; and
- Family resilience is supported and strengthened by holistic supports that focus on the family unit.

6 How Services Can Assist Families to Build and Maintain Family Resilience

Implementing strategies that enhance and encourage family resilience often presents a challenge for services (Patterson 2002:349). Family interviewees suggested a range of problems, good practice examples and ideas regarding how service delivery and supports could be improved. Stakeholders offered a number of suggestions for the types of services and supports families need and how they could be delivered. Many of these have been incorporated into previous sections of this report. This section summarises family and stakeholder interviewee responses and augments the practice elements identified in the literature (Muir 2008) to identify how services can assist families to build and maintain resilience.

6.1 Strengthening Families

Whole family approach

It has been identified in the literature that supporting family problem solving, mechanisms to maintain balanced family relationships and recognition of all family members are essential practice elements (Muir 2008). Support for a whole-family approach was strong among stakeholders, particularly for siblings who were described as often falling out of the sphere of focus. This was described as being increasingly the case as siblings (as well as the children with disabilities themselves) become teenagers. However, despite many policy statements about considering the 'whole' family, this often fails in practice. This is particularly the case for families who have a number of children with disabilities:

> There's an issue of uneven funding: one child in the family getting a lot and the other doesn't. In one family I know of, they get funding for two children but not their third – because the child doesn't have the same disabilities. Added to this, families talk to each other, they know what funding other families receive that they don't *(Social worker, South Australia).*

The concerns of family interviewees further reinforce the lack of holistic supports that work with siblings, parents and the family unit.

There are a range of practice elements services could incorporate that may assist families to strengthen, develop or build protective factors. These are listed below under some of the main protective factors families and stakeholders discussed. They should be viewed in conjunction with findings from the literature (Muir 2008).

Problem solving and communication

Findings

- Some families have difficulties drawing on strengths and resources to solve problems because they cannot identify what these are;

- Families can feel helpless if they have a problem they feel is outside of their control;
- Some parents may be under intense stress because of conflicts within the family;
- Parents sometimes isolate themselves socially because of problems relating to the child's disability; and
- A few parents find it difficult to help their children understand their sibling's disability and/or communicate as a family.

Practical support elements for service providers to consider

- Work with families to identify family strengths. Families are able to articulate many of their support needs, however, family strengths may not be one they are easily able to articulate or will bring up without prompting. Service providers need to initiate discussion of strengths with families;
- Provide tools and resources to assist families to effectively communicate, solve problems and manage behaviour. 'Tools' and resources could be drawn from disciplines such as social work, counselling and social psychology; and
- Offer counselling to parents as part of an integrated service. For example, while their child is receiving therapy, so parents are not required to seek this type of support out or spend time attending counselling sessions in addition to the appointments they have to attend with their child with disability.

Systemic changes

- For service providers to have the capacity to work with families on their strengths, at a systemic level service providers may require support to identify tools, train staff and work with families. A working group could consider funding the development of a specific 'resource kit' and training to assist services that do not have the capacity to support families in this regard.

Balancing the needs of family members

Parents of children with disabilities are under enormous pressure and time constraints. As with all parents, they prioritise needs, and their children's well-being is most often first and foremost. Most families interviewed had a hierarchy of addressing needs which reflected the following: child with disability; other children; individual parents (usually father first and then the mother); and the couple.

Findings

- Where there is a clear delineation of family roles between a distinct breadwinner (who does little caring) and a primary carer, it is difficult for the primary carers to do any activities for themselves;
- Couples open to sharing caring responsibilities (even if the father was the main income earner) are more likely to be balancing their needs with each parent spending time individually doing activities of interest;

- Couples are spending little, if any, time away from their children together;
- Sole parents get little, or no time for themselves;
- Many families are experiencing substantial stress about trying to meet the needs of siblings without disabilities;
- Parents acknowledged that their other children's needs are not always being met and that it is difficult for the parents to spend quality time with the other children; and
- Parents felt torn between addressing siblings' needs and completing required/recommended lists of therapies.

Practical support elements for service providers to consider

- Reassure parents about the importance of participating in activities for themselves and provide the support (e.g. respite etc) for them to do so (which isespecially important for sole parents);
- Offer holistic supports to assist families and couples to spend quality time together. For example, provide families with flexible funds so they could opt to forgo periods of respite and use the funding to have a holiday together;
- Provide assistance with therapy within the home to enable parents to focus on the other needs of the family;
- Provide resources, supports and programs specifically for siblings;
- Increase availability of support for siblings who may be in young caring roles; and
- Provide financial and caring support to assist families to meet the needs of all family members.

Systemic changes

- Funding models could include a specific statement that support will be provided to services to support activities that allows 'family time' of every configuration: the family unit; parents as individuals; parents as couples; siblings as individuals; child with disability and siblings; child with disability as an individual, etc. There will be built-in overlaps, for example: enabling couple time could well mean 'sibling-together' time, or individual time for the kids. Funding and service models could be explicitly designed to enable families to receive whichever constellation of family 'times' they need.

Social support and family times

Findings

- Sole parents appear to be dislocated from their local communities (not emotionally or socially linked);

- Fathers report not having anyone other than their partners to talk to about issues raised by having a child with disability;
- Even if parents are well connected with families and friends, this does not always translate to them being able to use these connections for emotional or practical support (7 of the 11 families interviewed stated they do not get emotional and/or practical support when they needed it); and
- Families socially isolate themselves by declining invitations or avoiding activities they feel are too difficult to manage as a result of their child's disability.

Practical support elements for consideration

- Sole parents may require assistance to network within their communities;
- Network fathers in similar situations to provide them with some emotional support;
- Eligibility for access to services should not necessarily be based on people's connection to family and friends because even if there are numerous connections they may not be providing tangible support; and
- Provide integration assistant support for whole families to participate together in activities they may not otherwise have attended. For example, enable respite carers to attend social and community events (that the family did not feel they could attend because of the difficulty in caring for their child with disability and other children) with the whole family to provide additional support for the child with disability. This is especially important for sole parents.

Systemic changes

- Investigate the viability of an online source (and perhaps other sources) of support for fathers who have a child with disability;
- If informal support levels are to be used as a criteria for service eligibility, it has to be meaningfully assessed as some families have strong connections to family and friends, yet they do not have practical support in regard to their child with disability; and
- Community support groups, organisations and government services need to offer assistance with childcare (perhaps in the form of an integration assistant) to make it possible for children to attend activities and events with their parents.

Future hopes and risks

Findings

- Families hope for big picture outcomes, such as happiness and a good education for their children, and smaller goals, such as access to required services and support and breaks from daily routines of therapies and appointments;
- Families worry about their child getting older and the implications of this;

- A number of families are concerned about balancing the needs of the family with financial income (most families could not afford the goods and services they feel are essential for their child with disability);
- Some parents are stressed about future needs, such as requiring a one-story home (instead of a unit with stairs) or moving away from a supportive community to increase access to services; and
- Families worry about the siblings of their child with disability becoming young carers.

Practical support elements for consideration

- Work with families to identify realistic goals and steps to achieve them;
- Forward plan with families for the short-term future – e.g. 'what supports and services need to be accessed or what changes made to make the next twelve months easier?'; and
- Work with families to identify perceived future risks and strategies to deal with these risks.

Services need to consider in conjunction with families: What can be done *now* to achieve the desired outcome for this child? What needs to happen *in the short term* future? What needs to happen *in the long term* future? This present and future oriented thinking needs to be an explicit component of operational planning.

Systemic changes

- Support families so they do not have to leave their rural networks/community to increase service access; or, if families are require to leave, actively support them to settle in new areas through networking and the provision of information;
- Provide families with financial support – management, information regarding the list of financial supports they can access, practical support to purchase goods and services their child needs because of their disability, and ensure parents are able to work (if they want to) by adequately supporting their child;
- Ensure families are receiving adequate support without older children having to leave school early to fill a substantial caring support role (especially in sole parent families); and
- The broad intersections between disability, education and workforce participation need to be recognised as operating for families, as well as the child with disability: lack of support for a child with disability may mean reduced employment of parents and educational attainment of siblings. This relates to a systemic function that requires a long-term approach: a whole-of-government position paper would be an excellent first step in getting the issue 'onto the radar'.

6.2 Strengthening Services to Effectively Support Families

Learning about disability: accessing information

For most families, getting access to information about appropriate and available services is a challenge. There was widespread frustration among the families that this information was not provided at the time of the assessment or as an ongoing process. Learning about and getting access to appropriate services is an important step in families being able to adjust to having a child with disability.

Stakeholders identified two distinct types of information families required: general information regarding disability and specific knowledge about a particular disability or child's situation.

Disability 'folk knowledge'

Much family resilience was discussed as relying on what could be termed as 'folk knowledge': how to navigate systems, learning what was 'out there' in terms of supports and services, what their rights were, what was going on in terms of policy and legislative developments – this information was best delivered in a somewhat informal manner.

This kind of information provision was a core business of the advocacy groups. Information provision 'on the street' or over the phone was a key strategy. This was particularly important in the case of receiving feedback from parents in return, as other strategies were found to be less successful:

> I'll give them leaflets if I see them, have a chat when I'm out and about and see someone on the street *(Family advocate, NT).*

> I tried to, through newsletters, get people to respond back. If I see them in the street, they give feedback then. But it's difficult to get them to commit to paper *(Family advocate, NT).*

Workshops conducted by the NSW advocate were conducted 'on tour' – going to the families, rather than families travelling great distances.

Their own child and family

Opportunities for parents to learn about the particular needs of *their child* are best served by a different route. Accessing developmental services – such as, physiotherapy, speech therapy, occupational therapy and dietetics – was best accessed by families in the form of a 'one-stop shop'. Being able to see different professionals in the one location and on the one day was preferable as having the flexibility to respond to their child's changing needs:

> Researcher: So you would rather trade off the convenience of having a tiny amount of therapy in your home to having sustained, group work?

> Parent: Ten million times. I would much rather trade off the travel and losing a day's pay for seeing all the services.

This type of support also facilitates necessary communication between therapists working together to meet children's needs.

Dedicated transport to therapies for those without cars was raised by a family advocate as a particular issue for the NT. Indigenous families would be the most likely population to require such a service, and thus, the service was suggested to be tailored to them with their input.

To ensure families receive sufficient information regarding disability in general and their child's specific situation, families require a co-ordinating individual who can network them with people able to share the information required (this is further discussed below in Section 6.3).

Timely access of services and transitions

An important consideration identified in this research, and one that is particularly pertinent to young children, is timely service provision. All stakeholders interviewed raised this as a special area for attention. Receiving appropriate and effective support during critical periods, such as times of heightened stress like transitions, was identified as important by stakeholders and family members. The birth and assessment period was particularly difficult for all of the families interviewed.

The timing of service provision in terms of child development was also raised as a paramount issue for children with disabilities:

> …children have a different time scale on their needs. You're looking for therapies now that can enhance future lives. Adults are looking for maintenance type things. Adults have much longer timeframes generally: children have distinct windows of opportunity *(Family advocate, NT).*

This was particularly important for families who were aware of the importance of early intervention and developmental stages. They had a window of opportunity for their child(ren) to access services, yet there were delayed assessments for eligibility and rejections for services that parents felt were critical to their child's development.

Family and service provider recommendations about accessing services

- Increase the provision of information for families at transition periods about their child's disability, services and supports available and how to access these supports.

Systemic changes

- Maintain commitment to early intervention and prevention approaches;

- Base service frameworks on developmental timeframes specific to children: timely, rapid responses are of central concern;
- Train doctors/specialists at 'breaking the news' to families about their child's disability;[12]
- Work with hospitals, doctors, specialists and services to ensure increased availability of information for families at birth, assessment and other transition stages about the services and supports available; and
- A commitment from governments and service providers that the availability of services would be increased so that children with disabilities would not be competing for limited places and families receive support before they go into crisis.

Effectively delivering support to families

Consistent workers

Across all service types, a common theme was consistency: changing workers meant matters were not always followed through. Consistency across the different domains of the child's life was also considered to be essential: 'They might get support at home, but nothing at soccer. Kids might have a couple of hours support at school, but no support transitioning it to home' (Government service provider, QLD).

Consistency needs to be particularly considered at points of transition. Change in one domain was likely to be associated with change in another. Thus, the response to change in one domain was likely to impact other domains:

> Often kids get the new beaut equipment, but then the host can't use them in their homes. So, the relationship has to end, or they have to do other things, or have to pay for taxis and other things to accommodate the equipment. Some things are not really well thought out. As the child grows, their needs have to be considered in *all* their environments, not just at home or school *(Social worker, South Australia).*

Availability and Quality

The treatment service providers offer – how they relate to families and the quality of service the child receives – is critical to effectively supporting families. Families reported sound relationships with general medical services and were likely to report positive relationships with community supports, such as child care services. This may be related to families' ability to choose their medical practitioner and child care service, rather than

[12] SPRC report on *Supporting families who have a child with a disability* for Families First Inner West included a model for delivering diagnoses for health and disability professionals, as well as research relating to provision of information at birth, diagnosis and assessment (Tudball, Fisher, Sands and Dowse 2003). Further research could build on this model.

having to take one assigned. Experiences with disability service providers were mixed. Families initially had high expectations of the supports they could receive from specific disability services and where these expectations were met families felt supported, but there was considerable disappointment and exasperation where this was not occurring. Families were likely to report good practice support as coming from individuals, rather than whole services. 'Exceptional' individuals were described as experienced, well trained, effective communicators, provided consistent and regular follow-up and produced both positive outcomes for the child and the family. Families were mixed in regard to how empowered they felt. Some parents gave in to service providers because of a fear they would not receive a service when needed.

Family and service provider recommendations about effective support

- Train staff working for disability services/organisations (from telephone operators to therapists) on how to effectively communication, negotiate, consistently follow-up and work with families;
- Work on developing and retaining quality staff and where possible maintain consistency with individuals working with families;
- Workers need to be able and willing to take a life course perspective to their clients with disabilities - therefore they do not work in 'childhood disability', but 'disability and families'; this means advertising positions and providing training explicitly as such; and
- Provide families with negotiating skills to make them feel like they have options and an informed say in the decision making process.

Systemic changes

- Introduce/improve quality standards for therapists within disability services and working for government departments. Quality standards introduced should include a family perspective; seek expert feedback on standards development from families themselves;
- Structure the disability support system to assist services to provide life course support for families; and
- Co-ordinators or facilitators need to be supported to be mobile, so that they can stay with families irrespective of changes in families' lives. This means realistic caseloads.

Flexibility

Flexibility is a core component of the recommendations in key literature (McCubbin et al 1997; Parker 2001; Patterson 2002; see Muir 2008). Family flexibility to enable them to adjust to change is most often the focus of the literature, but notions of flexibility also characterised stakeholders' responses. They referred to services needing the capacity to respond to individual family and child circumstances – a task that required a significant degree of flexibility.

Stakeholders involved in funding programs that were popular with families noted the flexibility in funding arrangements as key to their popularity: 'We don't have a list of what is in and what is out' (Government service provider, QLD).

Central to this flexibility is that families themselves are the main driver, according to their changing circumstances:

> Families can work and plan with their facilitator how they want to use that funding. Families could well have peaks and troughs; we don't lock them into any support program *(Government service provider, QLD).*

Thus, the services that families receive are tailored to where they are at:

> We have a planning process that we do with families. A family 'plan', but we don't call it a plan, as people focus on filling out the paper. We want the focus to be on the process. Once we know the kid meets eligibility, we go through what's needed as a family: goals, who will be responsible, timeframes. What the family wants the 'plan' to look like, for that family *(Government service provider, QLD).*

These notions of assisting families to maintain control over decision-making processes reflects equality and empowerment principles that underlie much of the literature in the field (Muir 2008). An important aspect of family's driving the planning process was described by a QLD government service provider:

> The issues were identified, then of each the question was asked: "How important is this for you at the moment?" We looked at the child's physical abilities in different settings: child care, home, and so forth. The physio was then organised to become involved and visit the settings and do a home visit, to see the home and so the family would be involved. Another issue not as important at that time was toileting. It was something they didn't need to start working on immediately, but we identified who would need to be involved and when it would start.

Family and service provider recommendations for service flexibility

- Offer flexible funding arrangements that may be directed toward the child and/or the family unit or other family members; and
- Base service provision on priorities families identify; that is, families drive the service planning process.

Systemic changes

- Introduce/increase flexible funding models that can be individually tailored to the family as a whole, the child, parents, other carers, such as grandparents, and/or siblings; and

- Focus further research on how funding models can achieve and sustain flexibility and responsiveness to families' changing needs.

6.3 Co-ordinated Support: The Facilitator Model

As the previous Section reinforced, families were eager for their access to services, supports and information to be co-ordinated. Stakeholders noted how parents of children who have a disability were noted by stakeholders as having to work much harder to get the same outcomes for their children as other children could expect to have, partly because of the 'running around' parents had to do:

> …funding at the moment is directed to a particular program or projects, rather than being individualised. So you've got to demonstrate your eligibility to each – if you need a wheelchair, you've got to demonstrate your eligibility, if you need respite, you've got to demonstrate your eligibility, if you need alterations to your home, you've got to demonstrate your eligibility. For some families and individuals, that can be quite a tricky thing for them to manage (*Government representative, ACT).*

There was strong support for a facilitator model as a means of assisting families in navigating the disability service sector; providing information regarding their entitlements; and offering emotional support. A facilitator was given as a possible solution to many of the issues stakeholders and family members raised in this study.

Facilitator models were popular because they:

- Minimise the requirement for families to repeatedly demonstrate their eligibility;
- Assist families to navigate the complex and confusing disability landscape, both perceived and experienced; and
- Allow parents to be parents, and not case managers or service coordinators.

The ideal facilitator model would have the following qualities:

- Committed to an early intervention approach;
- Well trained and well informed about the disability sector;
- Assigned at the time of diagnosis/assessment;
- Co-ordinates services to the child and family over the long-term;
- Improves co-ordination between services; and
- Effective communicator who provides families with information, emotional support and helps facilitate trust with other service providers, such as volunteers or respite carers;

- Social work or psychology trained, as their perspective is broad.

It was noted that the facilitator should not take on a 'gatekeeper' role, as 'that takes choice away from families' (Government service provider, QLD). The facilitator model also has the potential to ameliorate the drawbacks of the service co-ordination model to which many services currently adhere:

> One of the difficulties with the service co-ordination model is it doesn't go to the extent of case management where the key worker has a lot more involvement and knowledge of what is going on, and assists in being the key link between two or three services supporting the child. In the service co-ordination model, the parent has to take on that role […] and all the service providers see themselves as the only one and that's when unrealistic expectations are put on families *(Government consultant, Tas).*

From a governance perspective, it is important that future development of facilitator and other service provision models also consider the following systemic changes:

- How disability interventions interact with other interventions and family circumstances and what the outcomes are for all family members;
- Inclusive practices into mainstream life;
- Achieving consistency of support across all domains of a child's life – home, school, community life, and 'fun stuff';
- How interventions operate across all domains;
- How policies and practices to 'do things smarter' with current resources; and
- People from different demographic backgrounds, such as indigenous, sole parent and rural/remote families have particular needs that may require further address.

7 Conclusion

This research, funded by the Disability Policy and Research Working Group, aims to increase the understanding of family resilience in families where a child (0 - 8 years) has a disability and to inform policy and service provision supporting family resilience. A qualitative methodology was used to address the aims of the research. Eleven families, where children under eight years of age have a disability, and thirteen stakeholders, representing governments, service providers and advocacy groups, were interviewed. This report focuses on the key findings from the in-depth analysis of these interviews.

Family resilience is a process that includes three steps: crisis/adversity; drawing on strengths and resources to adjust; and adapting and resuming family functioning. The families interviewed for this research have experienced this process, to varying extents, on a number of occasions. They have confronted numerous adversities, they draw on internal and external strengths and resources to adapt to these situations, and they re-establish patterns of functioning after making some changes. Few families, however, felt that the needs of all family members were balanced with meeting the needs of the child with disability. The interviews reinforced that family resilience operates on a continuum that shifts and changes over time and is a process that families can repeatedly experience, often as a direct or indirect result of their child's disability.

The research found numerous protective and risk factors that families face in negotiating the resilience process. Having resources and strengths to draw on is critical for families to experience resilience. Most families have internal strategies they use to endure difficult periods or to solve problems; however accessing formal and informal supports also protects families. While the research found the majority of families receive informal emotional and/or practical support, almost two-thirds of the families reported that they do not get support when they most need it. Financial security also plays an important role in protecting families. Contrarily, families were at risk as a result of financial insecurity. This is potentially widespread because the majority of families interviewed reported an inability to afford the goods and services they believed were essential for their child with disability to achieve a reasonable quality of life. Finally, balancing individual family members' needs supported resilience. Most families found this difficult because of the time and financial resources required to support their child with disability.

Service provision can also facilitate and/or hinder family resilience depending on its availability, accessibility and quality. Numerous characteristics of service provision were found to support and hinder family resilience. Transitional periods are a critical time when a family's resilience may be tested. Support at the time of the child's birth and/or assessment is especially important, which includes getting access to appropriate information and services. Families are strengthened when their child receives access to effective services and where some positive outcomes are visible. Contrarily, families are placed at risk by repeated problems with the eligibility process, gaining access to services or where services are deemed ineffectual. Families are predominately content with and feel supported by mainstream health and community services, but some are dissatisfied and feel unsupported by the disability sector. Disability providers, however, who are experienced, well trained, resourceful, willing to find and impart information,

communicate openly and effectively with the family and provided options, help families in the resilience process. The co-ordination of supports and services that are holistic – that embrace the child within the family within the community – are also important factors in the resilience process.

There are numerous practice elements services can implement, develop or expand that work to strengthen families and help facilitate family resilience. For example, provide tools and resources to assist families to effectively communicate; reassure parents of the importance of balancing all family members' needs and provide resources to enable this to be achieved; offer holistic support to assist whole families, not just the child with disability; network parents, especially fathers and sole parents, within their communities; and work with families to plan for the future – both achieving goals and combating risks.

Practice elements can also be introduced that will improve service provision, meet the needs of families, and, in turn, support family resilience. Families and service provider interviewees recommended a range of good practice elements. Some of these include: base service frameworks on developmental timeframes and transitions specific to children; improve information provision; train doctors, specialists and disability service personnel on how to effectively work with families; increase the availability of services so children with disabilities are not competing for limited resources and preventative and interventionist support is provided; maintain consistency; improve quality standards for public therapist; and introduce/increase flexible funding models that can be individually tailored. There is overwhelming support among families and stakeholders for the expansion or introduction (where it is currently not available) of the facilitator model. This provides families with a facilitator who assists families to navigate the disability sector, co-ordinates appointments and provides information and emotional support.

Families where a young child has a disability can be supported through the resilience process if service providers assist families to build protective factors, plan for the future and counter risks; and if effective resources are available through holistic, flexible, accessible and high quality service provision.

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Appendix A:

Table A.1: Descriptive framework of practice elements to build, maintain and strengthen a family's protective factors

	Examples of practice elements (from Muir, 2002:21-22)
Family problem solving and balanced relationships	• Communication and problem solving skill training; • Parenting programs to assist with family based problems and interpersonal relationship conflicts; • Behaviour management courses; • Financial and caring support to assist families to meet the needs of all family members; • Specific resources/supports/programs for siblings (Bellin and Kovacs 2006:213; Gardner and Harmon 2002; Hastings and Brown 2002; McCubbin et al. 1997; Parker 2001:82; Patterson 2002; Smart and Sanson 2001)
Family hardiness	• Skill development for families to work together; • Assist parents to feel in control of situations; • Help families to maintain or build confidence that the family will stay together.
Social support	*Social networks – family and friends* • Provide financial support to ensure extra expenses of having a child with disability are covered so families do not have to sacrifice social and recreational activities; • Provide sufficient hours of respite care so that parents have the time to remain connected to friends and social and community activities; • Provide supports that link families together. *Public and community support* • Provide adequate services to support families where a child has a disability; • Inform families about what supports are available and how to access community and government supports; • Link families to services in their local community; • Empower families to have effective relationships with service providers; • Train service providers on how to build effective relationships with families (including listening and responding to families' needs, showing respect, earning trust and avoiding judgement); • Provide cultural awareness training to service providers and teach them how give information sensitively and effectively; • Target hard to reach families; • Recognise that families go beyond parents to include siblings, grandparents and extended relatives. Welcome friends to act as supports for parents/family members. Be flexible with meeting times to ensure both parents or a support person can attend with the primary carer. (Bartley 2006; Bellin and Kovacs 2006:213; Carpenter 2000; Gardner and Harmon 2002; Morison et al. 2003; Patterson 2002; United Kingdom Government Department for Education and Skills 2002).
Family time and routines	• Assist families to adapt routines and refocus goals when required and to deal with expected situations; • Let families drive this support – practitioners should avoid defining family functioning patterns because these will vary by family and differences in race, culture and ethnicity (Patterson 2002:356).
Hope	• Focus on what families can be hopeful for; • Assist families to develop or maintain hope for realistic outcomes and to change the nature of these hopes as situations emerge. (McCubbin et al. 1997; Morison et al. 2003:129; Patterson 2002).

	Examples of practice elements (from Muir, 2002:21-22)
Flexibility	• Assist families to adjust regarding changes to functioning - rules, roles, meanings and/or lifestyles. (McCubbin et al. 1997; Parker 2001; Patterson 2002).
Financial management*	• Provision of adequate financial support to meet needs of the child with disability, so families can meet these needs, are not in financial stress or sacrificing other family members' needs; • Provision of equitable access to child care and support for the child to access therapies and medical appointments, so parents can work desired hours; • Information and linking of free supports, such as toy libraries; • Provision of financial management skills training (where required). (Bartley 2006:15; McCubbin et al. 1997)
Truthfulness	• Active information sharing between service providers and families; • Assist families to access and understand information and share it with other family members (including siblings); • Hold group meetings where both parents or more than one family member can attend (this may have to occur outside of business hours); • Provide information/resources that are age appropriate for siblings.
Equality and empowerment	• Actively involve families in discussions and decision making. Talk 'with' families, not 'about' them or their child. (Dobson et al. 2001:25); • Assist families to build capacity to advocate for their child (education about rights, knowledge of supports available, support regarding how to advocate, support from community, such as other parents in similar situations); • Perceive, acknowledge and treat parents as experts of their child and be sensitive to their emotional side as parents; • Encourage and train parents and service providers to form partnerships that include negotiation and reciprocation. (Carpenter 2000:135; Dobson et al. 2001; Patterson 2002:357; Roberts and Lawton 2000:307; United Kingdom Government Department for Education and Skills 2002)
Spirituality/ meaning	• Referral, access to or provision of counselling by a professional who understands the situation families with a child with disability may be experiencing.
Health	• Provide families with the opportunity to look after themselves physically and mentally by offering periods of respite care so parents can rest and participate in recreation.